THE NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA GENERALLY KNOWN AS HELP PREVENT A COT DEATH APPEAL

England & Wales · Charity number 327033

Details

Other names	HELP PREVENT A COT DEATH APPEAL, THE NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA GENERALLY KNOWN AS "HELP PREVENT A COT DEATH APPEAL", BREATHING MONITOR APPEAL, BREATHING NEW LIFE CAMPAIGN, NARA - THE BREATHING CHARITY, NARA-THE BREATHING CHARITY, RAY OF SUNSHINE, THE BREATHING CHARITY, THE BREATHING MONITOR APPEAL
Status	Registered
Legal form	Other
Registered	1986-11-12
Register	View on the Charity Commission register

Contact

Address	Moulton Park Business Centre Redhouse Road Moulton Park Industrial Estate Northampton NN3 6AQ
Phone	01604494960
Email	info@thebreathingcharity.org.uk
Website	www.naratbc.org.uk

Activities

Objects: TO RELIEVE SICKNESS BY THE PROVISION OF RESPIRATION MONITORS OR OTHER MEDICAL EQUIPMENT FOR INFANTS WHOSE LIVES WITHOUT SUCH EQUIPMENT WOULD OTHERWISE BE AT RISK AND BY THE SUPPLY OF GENERAL MEDICAL EQUIPMENT TO SUCH INFANTS AND OTHER PERSONS WHO ARE SICK CONVALESCENT DISABLED HANDICAPPED INFIRM OR OTHERWISE IN NEED.

Activities: Provision of medical equipment, support, and advice for those suffering from respiratory illnesses or conditions.

Downloaded from opencharities.uk/ew/327033

Classification

- **How:** Provides Services, Provides Advocacy/advice/information
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, Elderly/old People, People With Disabilities

Geography

- Ireland
- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-04-30	£115,040	£120,425	-	-
2024-04-30	£123,074	£125,355	-	-
2023-04-30	£111,008	£99,499	-	-
2022-04-30	£101,218	£107,465	-	-
2021-04-30	£121,425	£113,378	-	-

Trustees

Name	Role	Appointed
ANN JIGGLE	Chair	
ELIZABETH ANN ATKINS		
FREDERICK WHITING		
Kary Anne Jiggle		2017-05-01

Downloaded from opencharities.uk/ew/327033

THE NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA GENERALLY KNOWN AS HELP PREVEN

England & Wales - Charity number 327033

Accounts



NARA - Annual Charity Report

FINANCIAL YEAR ENDING 30th APRIL 2025

NARA - The Breathing Charity, Moulton Park Business Centre, Redhouse Road, NORTHAMPTON, NN3 6AQ
Phone: 01604 494960 or 01604 497550 - Website: naratbc.org.uk - Email: info@thebreathingcharity.org.uk
Registered Charity 327033

NARA Annual Report - 1st May 2024 to 30th April 2025



In 1975, American singer-songwriter, Paul Simon, penned the lyrics to a song, '*Still Crazy After All These Years*'. It's tells a somewhat melancholy tale full of sentimentality and follows a seemingly lonely man who by chance meets a former lover in the street. They sit and spend the evening together, having a drink and reminiscing about old times. At the end of the evening, alone again, he's left wondering if those nostalgic thoughts override the reality of his situation.

Over the last few months, we've been looking back over the past forty years of the life of our charity, those same feelings of sentimentality and nostalgia kicked in too. Those early days were a struggle, with the organisation, the work and development of the charity, from the outset when we simply wanted to raise a few pounds to help anxious parents, now to a national charity and the first port of call for many patients, doctors, and surgeries.

So, after 40 years we ask ourselves, 'are we still relevant?'. We believe we are, if not more so than we were in 1984 due to the technological, social and cultural world we now find ourselves in, but will let you judge for yourself.

A quote from the parent of one of our first patients in 1984, who had used a respiration monitor due to their baby daughter stopping breathing said, *"To lose a child has to be one of the worse things anyone could have to experience, that makes your work very special and on behalf of my family we wish you well with your cause for the future."*



To lose a child has to be one of the worse things anyone could have to experience

Little did we know then that 40 years later we'd still be here helping, not only babies with respiration monitors, but a wider range of the community from birth, through to adulthood, middle age, and senior citizens who simply want to take a breath.

Moving on to 2024, a request came into the office, it was from a disabled young mother, Jenny, who has two young children. Her email read, *"Hi there, I have a friend who suggested I reach out to you. I'm a disabled wheelchair user with many chronic illnesses, one of which is severe asthma. I currently have an NHS issued nebuliser that isn't working very well. I have bought this up with my asthma nurse and she said in order to get new equipment I would need to be referred back to my consultant (which to be honest I do need anyway) but it will take a while (maybe 6+ months as it's not emergent urgent).*

In the meantime, she has advised me to either buy another (I'm low income disabled mum of two that's just been made homeless so it's not currently an option) or obviously attend A&E. The main reason for being issued home nebs was to keep me out of A&E firstly for the "normal" survive asthmatic reasons (no one likes being there all the time) but also because my immune system is often compromised or suppressed. My friend said there may be something you can do to help or you might be able to point me to someone who may be able to aid me. Thank you in advance for reading this."

To many, you'd think this was an exceptional request, but no, it's more typical than you'd expect. Indeed, a good number of our patients have these complex issues, as problems with their health have a great impact on their financial and living conditions too.

Whilst we whilst we cannot offer financial, or monetary support, our experienced team know how to signpost those like Jenny to other bodies who can assist with cost of living and associated problems. We helped Jenny with her nebuliser, she was delighted that we stepped in and helped so quickly.

Her reaction was, *"NARA is amazing, I cannot fault them at all. They contacted my doctor for approval, then, bing, bang, bosh, my new nebuliser arrived. Amazing!"*



Jenny helped by the provision of a nebuliser

Let's look at Jenny's request in more detail. She first mentions a friend referred her to us. On further investigation we found her friend had been helped by us, it shows our patients are pleased enough with our help, that they're willing to put others in touch with us for help too. Jenny's nebuliser was broken and she had been advised to buy a replacement, but simply couldn't afford to do that. Many of those who apply for help are on low incomes, so purchasing one, or indeed any other piece of medical equipment relative to respiratory conditions, is simply not an option.

"NARA is amazing, I cannot fault them at all. They contacted my doctor for approval, then, bing, bang, bosh, my new nebuliser arrived. Amazing!"

Jenny's need for the nebuliser was to help keep her out of hospital as she is susceptible to infection due to her immune system being suppressed. Again, most if not all of our respiratory patients due to their age, or their condition, are prone to various infections, which

unfortunately, seem to be prevalent in hospitals, doctor's surgeries or in public places, especially indoors, where there are a great number of people breathing in re-circulated air. Our aim is to improve the quality of life to, firstly the end user, or patient, and then their immediate family. The consequences of serious illness can, and in the main, does affect many aspects of family life.

Lastly, over the years, we have the experience and knowledge of being able to help those with financial problems, by simply directing them to local groups and other bodies that can lead to positive outcomes. Many local communities, especially in this day and age, have an increasing number of people, throughout the age spectrum, surviving on charity from churches and food banks in their area.

Following our help, Jenny posted on her social media, "Let me introduce you to an incredible charity, NARA, they have completely changed my life .. I cannot recommend them enough, they are true life savers."

Although life seems to be more complex in this day and age, it would appear our work has stood the test of time, we've evolved with those times and are still there to give a helping hand to those who struggle to breathe. Below are more examples of some of those assisted during this financial year.

Nebulisers

Since the pandemic, we seem to have more and more patients requiring nebulisers. Suffering from an ever-increasing list of breathing ailments from asthma through to more complicated and severe issues like bronchiectasis - a condition the NHS describe as where the airways in your lungs are damaged and produce a lot of phlegm, or mucus. It cannot usually be cured, but treatment can help manage it; and, idiopathic pulmonary fibrosis (IPS), where the lungs become scarred, which results in difficulty breathing. Whilst medication can arrest the progress of this, it's irreversible and in severe cases life threatening.

A cross section of some of those we've helped, this year by providing nebulisers and associated equipment include Annabelle, a young lady who has a number of conditions including brittle asthma, Elhers-Danlos syndrome (EDS), which is not normally associated with primary lung disease, but many associated with EDS experience debilitating respiratory symptoms. We gave her a portable nebuliser, firstly, as it is designed for ease of use and quiet operation reducing sensory overload and anxiety crucial for patients, such as Annabelle who also has autism, secondly it enables her to get out and about, enjoying the freedom of



Annabelle was delighted we could help her

movement rather than being house bound. She was delighted with our assistance, as her comment suggests, *"Wonderful, funky neb… Thank you so very much, this is going to be a game changer. I`m so happy."*

Next is Zabir, an elderly gentleman whose first language is not English, amongst his ailments is COPD that compromises his ability to breathe. His original nebuliser broke-down, and he was not able to afford a replacement. His local respiratory team pointed him in our direction, and we were able to give him the new



We went the 'extra mile' with Zabir

nebulisers he required. We went the 'extra mile' with this patient too, due to his vulnerability, visiting him on a number of occasions to ensure the nebuliser is kept clean and fully functioning and able to deliver his medication.

Melanie was another young lady who contacted us direct, we'd helped her previously, but her letter asked, *"Hi, I just wanted to contact you to see if you can help me again as you provided me with a portable Nebuliser last year, I`ve been making great use of it and now I`m improving with my physical health and going out and about more volunteering in schools with a view to doing my teacher training in the new year - it has proved to be a vital piece of equipment. However, in light of this, I was wondering if you could provide a portable nebuliser that is able to be charged via USB - so I can charge via my power bank when out and about for the day? Ideally with a power indicator to show the charge level? It would be a massive help!"*

We were delighted our previous assistance had helped her so much, giving her the freedom and independence to simply 'get on with her life' the epitome of our ethos.

Checking our suppliers, we provided her with a new lightweight portable machine, exactly what she wanted, she was delighted, saying,



Giving additional equipment to Melaine allowed her to take up teacher training

"The new nebuliser arrived today … it looks great, the USB charging feature will be perfect for me being out more doing my teacher training etc., Thank you"

Eileen, an elderly lady with a number of serious and severe respiratory issues, including



Eileen suffers from severe respiratory issues

asthma, bronchiectasis and tracheobronchomalacia (TBM) – defined as a collapse of the trachea and bronchial tubes causing breathing difficulties. It not only affects adults as research suggests that 1 in 2,100 babies have TBM symptoms and around 4-13% of those suffering airway problems have TBM. We were asked to provide her with a nebuliser to help ease her condition, which we have.

George, a middle-aged man, was directed to us via his local respiratory team. He is a long-term asthma sufferer with the added complication of having bronchiectasis too, which



George, suffers asthma plus complications

results in mucus accumulation that can trap bacteria causing lung infections. Again, we were able to provide him with the necessary nebuliser and support he needed, even though this was short term.

Lastly, we come to Victor, and elderly man who finds himself in extreme poverty, complicated by several illnesses, including heart disease, diabetes and breathing issues due to COPD. Our team found it necessary, not only to provide him with a nebuliser following a request from his doctor, but also extra care to monitor he was using the equipment provided properly and to ensure it was clean and functioning well to deliver the medication relevant to his illness.

We could go on, with many more patients helped, but we believe that the above give an adequate cross section of those seeking our



Victor is another of those patients who need extra help to ensure his equipment is working

assistance throughout this financial year.

Respiration Monitors, Apnoea and Tremor Guards

We have a rapidly growing list of patients who rely on monitoring equipment that alarms should they stop breathing. Initially, we helped by providing anxious parents with respiration monitors for their babies and infant children who suffered from apnoea or stopping breathing. Today, whilst still assisting the parents, medical equipment technology has moved on and now offers devices that help older children and adults who have conditions that lead to them stopping breathing. We refer to these pieces of equipment as apnoea and tremor guards.

Over the years, NARA has helped many, many anxious parents with respiration monitors for their babies, not simply to those who've suffered losing a child.

Highlighting patients helped by these monitors is firstly, Chester, a sibling of a former patient who was in need of a respiration monitor, due to his mother losing another sibling to 'cot death'. There are very few agencies within the healthcare



Chester's need for a monitor was due to his mother losing another sibling to 'cot death'.

system, even today, that can help a parent, or parents with anxiety following them previously losing a baby due to 'cot death'. A number of parents can be assisted to deal with the next born following the loss of a baby by using a respiration monitor. The comfort of knowing the monitor will alarm if their baby stops breathing gives them the benefit of time to deal with any issues. Not all, but a good number, of doctors and health visitors feel that this 'crutch' helps worried parents deal with such anxieties until their baby seems to have the strength to battle through the early stages of life.



Tilly's health visitor suggested we provide her with a monitor

Another baby we've helped from birth, is Tilly, who following a request from her health visitor, was given a respiration monitor. Her mother's twin sister had died of 'cot death' leaving Tilly's mother very anxious. We'd previously helped her older siblings, who are now doing fine – Tilly too.

We move on to 18-month-old Bonny who suffered severe norovirus, which according to the NHS, 'continues to grip the NHS with the number of beds taken up by patients with the virus nearly 150% higher than last year.' The virus is commonly known as the winter vomiting bug, it is unpleasant and not only causes sickness but diarrhoea too, which left Bonny with tonic clonic seizures -



Bonny needed an apnoea and tremor guard due to suffering tonic clonic seizures

previously referred to as grand mal epilepsy, and apnoea. Due to her seizures, which can result in sudden muscle stiffness, shaking and loss of consciousness, a normal respiration monitor would not have been appropriate in this case. A respiration monitor detects movement, seizures include much movement, so we provided her with an apnoea and tremor guard, which sensor works by using infrared light technology that detects the blood flow under the skin and transmits this wirelessly via Bluetooth to a tablet, where it is converted by software to continuously display the wearers heart rate. The tablet processes this constant flow of data and will raise an alert if the wearer's heart rate falls outside the normal parameters, or indeed if the patient endures a seizure.

Finally, there's another infant, Isla, who suffers apnoea attacks - stopping breathing, and Elhers Danlos syndrome, which we've discussed earlier in this report and how it affects respiration. Initially, we had provided her with a respiration monitor, but as she got older, we felt that one of the apnoea and tremor guards would be more effective for her, so she was given this, initially to work in conjunction with the monitor, but ultimately for the new equipment to replace the monitor.

Paediatric Healthcare Transition

Although, you will have read in our previous reports about the issues related to long-term child patients who move into adulthood. For the last couple of years, we are increasingly helping children, their parents and carers, that have either been referred by the hospital via new Paediatric Healthcare Transition Teams, or those that seem to have fallen between the 'cracks' in the system. This is where, due to age, youngsters elevate into the category of adulthood. A high value is placed on autonomy and independence, but for those with severe functional limitations "independence" may be unobtainable for those requiring substantial assistance in daily life with parents often bearing high intensity, and long term care giving.

It includes especially those children, who from an early age, have suffered from complex health conditions over a number of years, including many that were born with these ailments, diseases, or disorders. The hospital system of care and support has become like a surrogate or proxy family; such is their reliance on them.

A request along these lines is as follows, *"Hello, I was signposted to you by the Community Respiratory Team to ask about applying for a*



For those journeying from childhood to adulthood, who suffer from disabilities, their path can become difficult and confusing for both them and their families and carers

home nebuliser for a young person about to turn 18 years in the community that requires a home nebuliser and suction machine. If you could advise with how I apply for this, I would appreciate your support."

Whilst there are plenty of guidelines on paper which state the contrary, unfortunately, the harsh reality is that once a child turns 18, they become an adult and cannot be afforded the same help and support they have been used to. Age catches up on all of us, but to a child entering adulthood, suffering from a number of illnesses or conditions over a protracted period of time, see that care, help and support simply withdrawn, many at a moment's notice. It's not only unsettling and confusing for the patient, but their parents and carers too. For the patient, it's like the loss of their 'second family'. A mother of a 'new adult' caught up in this anomaly, told us her son's care had been withdraw, and the nebuliser and other medical equipment was to be handed back immediately. There was no warning given, nor smooth transition from childhood to adulthood. Her son, couldn't understand why those medical professionals at the hospital who'd given him much support through some dark periods of his life with both his physical and mental disabilities for many years, had been taken away, it was like 'a rug being pulled beneath our feet', as she described it. Whilst many of those who have given that care was sensitive to their predicament, the bureaucracy halted any further assistance, treatment, or help. In the above case NARA has stepped in to help with new equipment to replace that taken away, indeed we've helped to provide equipment to several young people referred to us by these new Paediatric Transition Health Care Teams, during this financial year. They not only suffer from respiratory conditions, but many other complex issues including a 17-year-old young boy, spastic quadriplegic cerebral palsy, profound learning difficulties, epilepsy, gastrostomy fed, scoliosis, bilateral optic atrophy and astigmatism (registered blind), hyper salivation, intermittent muscle spasm, non-verbal. Also, an 18-year-old young man, suffering epilepsy, four limb cerebral palsy, scoliosis, gastrostomy fed, an 18-year-old young lady, suffering recurrent respiratory infections, thick secretions, cerebral palsy, gastric reflux, and a 17-year-old young lady suffering asthma, bronchiectasis, anaemia, and hearing loss. So, we hope we've able to provide some comfort for them there. Nevertheless, for these vulnerable patients caught up in this situation, it's almost like they have to start again from scratch, with new hospital teams for their future care. A very traumatic period for the patient and their family.

Palliative Care

When one thinks of palliative care, it's normally associated with the more elderly people in society, or those who have at least had some sort of life, however, our first is four-year-old Felix, who has suffered respiratory failure, along with quadriplegic cerebral palsy, and a genetic disorder that causes serious lung and liver disease. He needed a portable nebuliser so he could be taken out to make memories. So, this was more for palliative care rather than long-term assistance with recovery as the outcome. Whilst it is difficult to deal with cases of palliative care it's much easier to accept than when the patient has not experienced those things that most of us take for granted. At such a young age, Felix has only taken the first few steps along his pathway.



Offering equipment and dignity for those needing palliative care

During this year, we've said farewell to several patients who wished to pass from this world to the next with a degree of dignity that has

been afforded to them. Many wish to be surrounded by family and friends, in their own environment rather than the confines of a hospital, or hospice. Unfortunately, not all of us have that option, but where it does, we're more than happy to lend a hand to family and carers by providing whatever medical equipment they need relating to their respiratory conditions, until the inevitable happens.

So, amongst others, we said goodbye to Patrick, Eric, Carole, Bani, Jon, and Harry – may they rest in peace.

Financial

Financially speaking, similar to many others, whether charity, business, or personal, this year has been a relatively difficult year. This is mainly due to the current global and national financial landscape, which has resulted in there not being as much disposable income available as in previous years, so we find ourselves around £10,000 short of our total income for the previous year. Nevertheless, despite this shortfall, and as mentioned in many previous reports, we are very fortunate over our history to have formed great relationships with many trusts, business, and individuals who have supported us financially, and this year has been no exception. We rise to this challenge and simply carry on. Indeed, on a positive note, we still have exceeded our aim to raise £100,000 per year by some £15,000. And still maintain above 80p in every £1 spent on the main objectives of our charity – this year almost 90p in the pound. Like last year, due to our minimal financial obligations, outgoing costs and commitments, we again feel we're in a very positive position.

Expenditure wise, due to our ongoing programme of replacing worn out, broken, irreparable, or pieces of medical equipment that may cause cross contamination, with brand new items, our fixed assets have not changed; due to the fact that this financial year has seen us purchase the same number of items as we have had to dispose of.

Due to increasing workload, we have increased the hours of our employed worker whilst in the main involved in admin duties, we found we needed extra help both on the medical side of things and fundraising too. With the medical side of things, delivering equipment to patients and co-ordination with healthcare professionals, especially with the new Paediatric Healthcare Transition programme (as mentioned earlier in the report), there is much more work involved with various agencies and the patients. Also, on the fundraising side of things, as well as providing assistance to those who wish to hold events for us, we've found it more challenging today, than it has been previously to try and raise historically similar amounts. Hence our fundraising costs have risen too, but although maybe not significantly assisting income this year, we're sure this will increase our funds over the following years.



We would like to express our gratitude from those who have donated or fundraised for us this year. Whilst many of those who support us wish to remain anonymous, those below have given us permission to use their details.

The Persula Foundation has recurrently helped us financially with our children and young persons projects.

Special thanks too to both The James Wise Charitable Trust and F B Coales (no 4 Family) Trust, again for their longevity of support

The following represent just a handful of the businesses who have been there for us for 30 years, or more – thank you.

The Paint & Bodyshop, Beckenham; A Abbott & Sons Funeral Directors, Rushden; Priory Press, Rushden; Wroughton Building Contractors, Swindon.



Finally, we once again received significant funding from, The Sporting Bears. NARA would like to express sincere thanks and gratitude to all who have helped financially.

Conclusion

We began this report by paraphrasing the Paul Simon song, '*Still crazy after all these years'*, changing the word crazy for relevant. We hope through this report and by the longevity of our charity we've been able to prove that we're still, not only very relevant in this day and age, but have moved with the times to offer new technology and embrace those who suffer many complex problems as well as significant respiratory issues in today's world.

To sum up, this is what we've achieved this year. We've continued to service over 1,200 of our core long-term patients with various types of equipment, replacing over 30 pieces of equipment for existing patients due to fair wear and tear, or simply just worn out due to continued use, and those that could cause cross-contamination. We've visited around 400 patients, many of them who make up our core long-term list and the remainder being new patients taken on this year. Our 24/7 helpline has kept us busy throughout the year with new requests for monitoring equipment, mains and portable nebulisers, constant requests for accessories and spares to deal with breakdowns, to ensure equipment

gives peak performance for another year. Again, we dealt with around 2,500 calls, both incoming and outgoing, some involved those needing new equipment, others simply wanting advice, whilst some of our lonely patients just wanted to chat, having a talk with someone who had time to listen. Our total patient numbers increased by almost 20 per month, in the main for nebulisers, but also includes respiration monitors and apnoea and tremor guards too.

We've kept in touch with and offered advice to many patients and other people via our various social media sites. Many patients are members of our online community and have been so for many years. They find it a safe space where they can openly share feelings, be vocal about their condition(s), express support for other group members and receive support from those with similar issues.

Unfortunately, due to age, illness, or being one of our palliative patients, we lost several of our 'family' throughout the year. We trust our intervention, however great or small, improved their quality of life, or gave them an opportunity to spend their last days with dignity. All in all, we've been kept incredibly busy.

We'd like to finish our report by rewording another song title, this time the classic Motown single by the Four Tops, '*Reach out I'll be there*', to 'reach out we'll be there'. Indeed, over the years, as we've mentioned we have become the first 'port of call' for many respiratory teams the length and breadth of the UK. Clearly, we've been able to help many of those requesting our support.

However, we've only been able to help with the continued financial support from many donors, be they trusts, businesses, groups, or individuals - we would like to take this opportunity to thank each and everyone. We trust you'll continue, just see what we can do with a little help from you - our friends.



We got by, thanks to a little help from our friends at

NARA The Breathing Charity
Registered Charity 327033

THE PROCESS OF HELPING OUR PATIENTS



Prospective patients read what we offer either through our website, or reading our information leaflet, or via their GP or health professional





We're then contacted by phone, Email, or letter. Our staff take full details to determine how and if we can help.





Once we agree on a course of action, we ask the GP or healthcare professional responsible for the patient to sign an authorisation form. Once complete we can pack the equipment ready to deliver





Delivery of the equipment is usually via courier, Royal Mail, or our own representatives. We offer a 24 hour helpline to assist patients set up and enable them to keep their equipment in good working order







Once the equipment is received, our patients are called regularly to ensure all is working well





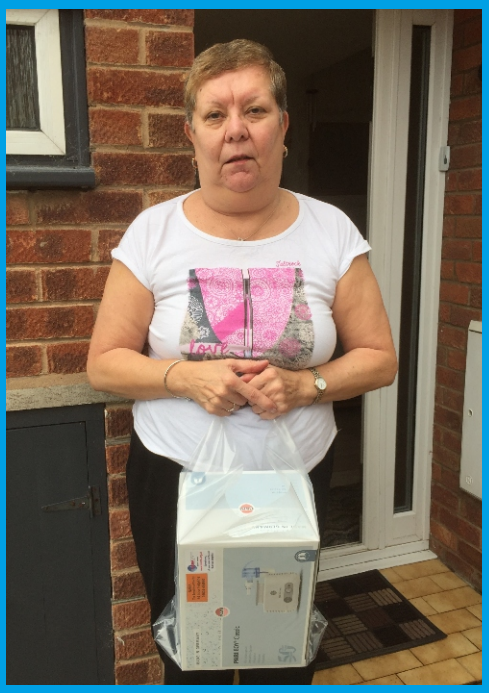


NARA - Annual Charity Accounts

FINANCIAL YEAR ENDING 30th APRIL 2025

NARA - The Breathing Charity, Moulton Park Business Centre, Redhouse Road, NORTHAMPTON, NN3 6AQ
Phone: 01604 494960 - Fax: 01604 497550 - Website: naratbc.org.uk - Email: info@thebreathingcharity.org.uk
Registered Charity 327033





Caring for all generations

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Charity Information

Trustees	A Jiggle E Atkins K Jiggle
Charity Number	327033
Charity Offices	Moulton Park Business Centre Redhouse Road Moulton Park Northampton NN3 6AQ
Examiner	Paul Connolly, FCCA. The Tax Shop Group Ltd G14, Moulton Park Business Centre Redhouse Road Moulton Park Northampton NN3 6AQ
Bankers	Barclays Bank Plc 267 Wellingborough Road Northampton NN1 4YD

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Independent Examiner's Report

Report to the trustees	**National Association for the Relief of Apnoea**
On accounts for the year ended	**30th April 2025**
Charity number	**327033**
Set out on pages	**Pages 3 to 6 inclusive.**
Responsibilities and basis of report	I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 30/04/2025. As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act"). I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.
Independent examiner's statement	I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect: - the accounting records were not kept in accordance with section 130 of the Charities Act; or - the accounts did not accord with the accounting records; or - the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination. I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.
Signed:	P. Connolly **Date: 04/02/26**
Name:	**Paul Connolly, FCCA.**
Relevant professional qualification(s) or body	**The Association of Chartered Certified Accountants**
Address	G14, Moulton Park Business Centre, Redhouse Road, Northampton, NN3 6AQ.

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Statement of Financial Activities for the Year Ended 30 April 2025

	Notes	2025 (£)	2024 (£)
Incoming Resources			
Donations from Grants, Trusts, Companies and Individuals	**2**	115,040	123,074
Direct Charitable Expenditure			
Medical Equipment, Care and Support		104,565	108,691
Other Expenditure			
Fundraising Costs		4,039	2,563
Management and Administration of the Charity	**3**	11,821	14,100
Total Expenditure		120,425	125,355
(Gains) and losses on revaluation of fixed assets for the charity's own use			(6,025)
Expenditure after exceptional costs		120,425	119,330
Net Movement in Funds for the Year		**(5,385)**	**3,744**
Total Funds Brought Forward		42,992	39,248
Total Funds Carried Forward		37,607	42,992

There were no recognised gains or losses for 2025 other than those included in the Statement of Financial Activities.

The notes on pages 5 and 6 form part of these accounts

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Balance Sheet as at 30 April 2025

	Notes	2025 (£)	2024 (£)
Fixed Assets		36,119	36,119
Current Assets			
Cash at Bank and In Hand		1,778	7,193
Current Liabilities	5	(290)	(320)
Total Assets less Current Liabilities		37,607	42,992
Capital			
Unrestricted Funds		37,607	42,992
Total Funds Carried Forward			

Approved by the trustees on 20/2/2026 and signed on their behalf

Trustee

The notes on pages 5 and 6 form part of these accounts

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Notes to the Accounts

1 Accounting Policies

1.1 Basis of Preparation of Accounts

The accounts are prepared under the historical cost convention and include the results of the charity's operations which are described in the Trustees' Report and all of which are continuing.

The accounts have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014

The charity has taken advantage of the exemption in Financial Reporting Standard 102 (FRS 102) from the requirement to produce a cash flow statement on the grounds that it qualifies as a small charity.

1.2 Income

Voluntary income and donations are accounted for as received by the charity. The income from fundraising ventures is included gross, with the associated costs included in fundraising costs. No permanent endowments have been received in the period.

1.3 Value Added Tax

Value Added Tax is not recoverable by the charity, and as such is included in the relevant costs in the Statement of Financial Activities.

1.4 Fundraising Costs

Fundraising expenditure comprises costs incurred in inducing people and organisations to contribute financially to the charity's work. This includes the cost of advertising for donations and the staging of special fundraising events.

1.5 Management and Administration Expenditure

Expenditure on management and administration of the charity includes all expenditure not directly related to the charitable activity or fundraising ventures.

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Notes to the Accounts (continued)

2. Incoming Resources	2025 (£)	2024 (£)
Donations	114,860	122,854
Medical contributions	180	220
Total	115,040	123,074

3. Management and Administration of the Charity	2025 (£)	2024 (£)
Office Rent and Services	7,481	8,880
Administration staff	3,920	4,800
Independent Examination	420	420
Total	11,821	14,100

4. Staff Costs

No remuneration was paid to trustees in the year, nor were any trustees' expenses reimbursed. The staff costs were:

	2025 (£)	2024 (£)
Wages and Salaries	11,760	4,800

The average weekly number of staff employed by the charity during the year was as follows:

	2025	2024
Administrative	1	1

5. Current Liabilities	2025 (£)	2024 (£)
Accrual for Independent Examination fees	290	320

THE NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA GENERALLY KNOWN AS HELP PREVEN

England & Wales - Charity number 327033

Accounts





FINANICIAL YEAR ENDING 30th APRIL 2024

NARA - Annual Charity Report

NARA - The Breathing Charity, Moulton Park Business Centre, Redhouse Road, NORTHAMPTON, NN3 6AQ
Phone: 01604 494960 - Fax: 01604 497550 - Website: naratbc.org.uk - Email: info@thebreathingcharity.org.uk
Registered Charity 327033

NARA Annual Report - 1st May 2023 to 30th April 2024



It's difficult to believe and quite humbling, in equal measure, to understand that our charity was founded some 40 years ago, in 1984. Difficult in wondering where those 40 years have gone, time certainly moves very fast; humbling to believe the British public have supported our cause for so long, not only with their donations, but their encouragement too.



Kary and Iain with their respiration monitors



Kary today - has a passion for motorsport

NARA was founded following the plight of two Northampton babies who suffered apnoea episodes, which means they kept stopping breathing for no apparent reason.

Our story began on an early summer's day in June 1983, when the first baby, Kary, was just six weeks old when her parents found her blue in her carry cot. They panicked and probably did all the wrong things but got her breathing again.

Within the hour Kary had stopped breathing for a second time. Again, panic set in, but her anxious parent got her breathing. This time they took her straight to the doctor, but when they arrived in his surgery Kary was rosy cheeked, smiling and showing no signs of there being anything wrong. After relaying the apnoea incidents to the GP Kary's worried parents were dismissed as being neurotic and exaggerating the two incidents.

Back at home, life was very tense for Kary's parents as one of them was always looking over her to ensure she didn't stop breathing again - day and night. With two other children to look after, time was very tense. Thankfully a visiting health visitor witnessed Kary having a further episode of not breathing, and at last her parents were taken seriously. Kary was admitted to Northampton General Hospital where various tests were carried out, unfortunately with no direct reason for the apnoea episodes, it appears she 'just forgot to breathe'.

Kary's parents were told to purchase a respiration monitor, which would alert them should she stop breathing again. It took a while for them to source a reliable product, but they did. It was truly a life saver, Kary had more apnoea episodes during her next two years, many times the alarm would sound, and she'd start breathing again, but on 15 occasions she had to be resuscitated. The monitor used was the Graseby MR10, a light, portable monitor, that uses a pneumatic sensor attached to the baby's tummy. This was preferred to the mattress monitors available, which only operated in a static position, like a baby's cot, not in a pram or carry cot in a car. Kary's parents had learned very early on, that cot deaths, or in their case, apnoea attacks, didn't just happen in cots, it could happen at any time and anywhere.



Iain today - is a chef in Costa Rica



Kary at a few months old



Iain and his mum

The second baby was Iain, sadly his mother had had two cot deaths previously. In December 1983, Iain was admitted to Northampton General Hospital following him suffering similar apnoea episodes to Kary, again for no apparent reason. His mum was told to buy a respiration monitor, prior to him being released.

Family and friends of Iain's mother immediately knocked door to door around the area they lived trying to raise enough money to purchase a monitor. Living nearby, this is when Kary's parents and Iain's family and friends first met. The appeal for Iain's monitor was very successful, it not only raised enough



The 'original' MR10 monitor was £300



Christina and Adele in 1984 …



… today, they both live in Australia

money for his monitor, but enough to buy more. At this time, respiration monitors cost £300, but another £100 was needed for disposable sensors.

1984 -1994

In early 1984, Kary's parents and Iain's mother united in their hope to raise further funds to purchase more monitors for similarly placed parents of children suffering apnoea.



BABY APPEAL GETS £1,000

Kary Jiggle

By Simon Radley

ENOUGH cash to buy two machines for preventing cot deaths has been donated to the appeal fund featured in the Post two weeks ago.

Readers rally round

Soon, enough money had been raised to purchase six monitors and six packs of sensors, with a surplus of money available to keep the monitors running for at least a year. The hope was to donate these monitors to Northampton General Hospital, not for hospital use, but for home use. Whilst in hospital, monitors were available, and 24/7 care by nursing staff supported these babies, but when they were home there was nothing. This meant parents would have to sit by their baby to ensure they continued to breathe normally. This is where the help was needed. Unfortunately, the hospital couldn't guarantee that the monitors could be used in this way, they'd be used for ward use in the main. That wasn't an option for the group, now called 'Help Prevent a Cot Death Appeal', who'd raised the funds, so they left the hospital with the monitors to consider their next move.

Not too long later, due to local press exposure of what we'd achieved, a local mother from Northampton contacted us, Christina, unfortunately she had suffered the loss of a child, a baby daughter called Sarah, through 'cot death'. Christina had just given birth to a baby daughter, Adele, and was very anxious that she may lose her too. She asked if we could provide her with a respiration monitor. Of course, we wanted to help, but we had to look closely at the logistics of doing just that. Before we could give any help. Firstly, we needed to contemplate the following questions; legally how do we stand loaning the equipment, how do we do this with the approval of medical staff responsible for the child, what support we would need to give both mother and child, and who would offer resuscitation advice.

We took advice from many bodies including solicitors, GPs, paediatricians, health visitors and the Red Cross, who were expert on resuscitation for both adults and children. We had particular help from Dr Peter Swift a leading paediatrician from University Hospital Leicester and much input from Graseby Medical the manufacturers of the respiration monitors. We managed to get enough information together to allow us to help Christina and her daughter Adele within days of her request. This was the very moment our appeal became fully operational.

We'd like to take you on a journey and look back over the past 40 years, recalling some of the key moments, and illustrate a number of patients we've helped and, like Adele, show where some of them are now. Also, to see how our initial local 'Help Prevent a Cot Death Appeal' developed into a national registered charity, nowadays helping others of all ages who suffer chronic respiratory issues.

It was during the summer of that year, via national tv and newspaper coverage, when we heard of the sudden passing of a baby girl, Elizabeth, in Somerset. She was a sibling of IVF triplets. Our situation was that we had a number of respiration monitors on a shelf doing nothing. We therefore contacted the hospital to ask if the surviving siblings, Jennifer and Robert, would benefit from the use of a monitor each, especially after being discharged. We were told by their paediatrician they would. So, we set off to Somerset to deliver the monitors, explaining fully how they worked and insisting the parents were given resuscitation training. A few days later the babies were discharged. The story of these triplets had caught the imagination of the national press, and a number of newspapers sent staff to cover the baby's leaving hospital.

A curious journalist asked what the little 'ticking' boxes were. They were told about the respiration monitors by the parents, who also told journalist to contact us in Northampton to find out more about our appeal.



TWINS HELP TO BEAT A KILLER

Cot death mum campaigns for 'Sleep-bleepers'

We found the publicity to be a double-edged sword

The publicity of this one event significantly boosted awareness, but we found it to be a double-edged sword as more people wanted help than we could possibly deal with. However, a number of other events saw us gain financially too. We were contacted by a programme researcher of the then popular tv series 'Bullseye', courtesy of a contact with one of the stars, Tony Green, who was the scorer, and worked closely with the main presenter, Jim Bowen. The 'Bullseye Christmas Special' was to support charities, rather than members of the public. In the programme, the scorer Tony Green, became the dart thrower, and Ann Aston, who'd previously worked on another successful tv show, 'The Golden Shot', would calculate his score. Ann played her part on the show by giving the appearance of struggling with simple arithmetic when



Jim Bowen and Tony Green of tv's Bullseye fame

calculating contestants' scores. In the Bullseye Christmas Special, Tony Green failed to score maximum points for us, but Ann's spurious adding up allowed us to be given the maximum £300. Jim died in 2018, and we learned that Tony sadly passed away during this year - he was a great support to us in the early days of our charity.

From there, public interest in our work grabbed the attention of producers of BBC's weekday 'Pebble Mill at One' lunchtime show.



A few days after we'd been featured, we had a phone call at around 2am in the morning, surprisingly from the former British and European featherweight boxing champion, Barry McGuigan. His then baby daughter, Danika, who was just a few weeks old, had suffered apnoea attacks and he was beside himself with anxiety, not knowing what to do. After talking with doctors caring for Danika, they agreed both she and her parents would benefit by the use of a respiration monitor. Barry was so thankful for our help, he paved the way for a number of fundraising projects, firstly to fund further monitors, by organising an amateur boxing evening at the Cafe Royal in London, which raised enough money to buy 30 monitors - at that time, our biggest fundraising event by far.



Filming of the Five A Day video

He later helped fund an educational video showing parents when and how to resuscitate their baby. It was called '*Five A Day',* as during the 1980s that's how many babies died of 'cot-death'. This was done in collaboration with the Royal Society of Medicine, and was the first video of its kind in the U.K. - it also won an award from the British Medical Association.

By early 1986, we had completed the necessary paperwork and legalities to be already formally registered with the Charity Commission, with a full title of the National Association for the Relief of Apnoea (NARA). In mid-1987, just three years after we loaned our first respiration monitor, thanks to the generosity of the public, we had helped 300 babies, their parents and/or carers with respiration monitors. To celebrate this, and more importantly, to get these babies and their parents together, and, of course, to continue the stream of positive publicity we held a party. This was held at the Cafe Royal, London, and again kindly supported by them. The event attracted a good number of families we'd helped, and a number of then celebrities. It was a really special day, giving us a chance not only to meet and greet these families, who'd been through a trying time, but to thank some others who'd been instrumental in helping us with the support


NORTHANTS POST

POST APPEAL FUND

BARRY WEIGHS IN BEHIND CHARITY

After McGuigan baby girl 'dies' three times

½PRICE PATIO DOORS or FREE FRONT or BACK DOOR

Albest Windows NORTHAMPTON 28604

Inside: Looking for a Job? Turn to Pages 51-54 for top choice

Grateful for our help, Barry McGuigan, MBE, helped raise money for a number of projects









The NARA party at the Cafe Royal, London, was a great success Parents were able to engage with other parents whose babies had breathing problems



David Amess MP attended with his wife


STARS KO'D BY SUPERKIDS

LUCKY-to-be-alive toddlers, including a number from Northampton, celebrated in style at the weekend with a massive party at the Cafe Royal, London.

For all the 300 babies present have cheated near death and been helped by the Northampton based charity Help Prevent a Cot Death Appeal.

Above: Two-year-old Sam Desborough, of Kingsthorpe, gets a cuddle from Blue Peter star Janet Ellis.

Right: Radio 1 DJ Janice Long chats to Angelique (3) and Simon Collard (4) from Mawsley, Northampton.

Top left: "That's Life" star Bill Buckley with Tamsion Sheppard (11 months) of Longlands.

Left: Christopher Lillycrapp, children's TV presenter, with Mark Davies, 13 months, from Weston Favell.

Above: Maesing Geoffrey from Rainbow is Nicky Richardson (2) from Abington.

The local newspaper gave thanks to the various celebs, who were amazed to be invited and hear their stories

and advice to help us get our now, national charity, up and running. Special thanks here must be given to the late Conservative MP for Southend, Sir David Amess, who was not only a font of knowledge, but continued as a significant fundraiser for us for a number of years after.

Thanks to a number of then celebrities attending, a pantomime performance given by an amateur dramatic society, and a magician adding entertainment, the children, their mums, dads, brother, sisters and carers, a true party atmosphere was generated. Parents, who once seemed isolated with their baby suffering near death experiences, were now socialising with others who'd been in a similar situation. This was valued by many; their feeling of remoteness had been banished in one afternoon. Yes, the Cafe Royal party was a fantastic and very worthwhile event.

We had had some great success providing monitors and support to parents, these were highlighted at the Cafe Royal party, indeed, many of those helped wrote to us, post event, with similar words to those send to us by a mother, Alison, from Bedfordshire, after we'd given her a monitor for her baby daughter, Florence. In her letter she wrote, *'I would like to thank you very much for the use of the alarm, which has given me a great peace of mind in those vital early months and also thank you for your kind attention. I must also add that our children very much enjoyed the party in London and my eldest daughter still talks about it. It must have involved a great deal of work and thought and was well worth the effort.'*

Looking back, it a shame that we've not been able to repeat this event, but, to date, the opportunity to do so has never arisen - one day, maybe?

However, we did have some tragic stories too, including a 16-year-old unmarried mother, from Northamptonshire, whose baby suffered a traumatic birth. Baby Christopher was severely brain damaged, and his mum requested a monitor, which we gave. After a few short weeks, the very brave mother said that Christopher had suffered a number of seizures, each one made his condition much worse. She wanted to give the monitor back, it had helped her 'get to know him', but she didn't want to intervene and resuscitate her baby son should it happen again. A few days later Christopher sadly died, but what a brave decision, by such a young mother.

Also, we helped a baby boy, Luke, who suffered apnoea attacks and had not had any episodes for a number of months. Luke's mother felt confident that he was finished with it. A few months later we learned that Luke's dad had been killed in a car crash. If that wasn't bad enough, just another few months later the family home caught fire during the night - all perished, except for the mother. There are no words to aptly describe her loss, nor her absolute despair.

On a brighter note, 1988 was an important year for both Kary and Iain, who were now, preparing to begin their first day at school. This seemingly simple event was considered by the parents of 'new' babies we were helping with equipment, as a 'light at the end of a tunnel' sign - if these two children, who were poorly at a very young age, could survive, then their child could do the same.



Iain and Kary started school in 1988
It was a significant time for them both

During the early 1990s, due to a serious illness to one of the Trustees, the charity, whilst continuing to operate, trod water for a couple of years, keeping a relatively low profile, but still offering help and support when needed. This was possibly one of the lowest ebbs we'd suffered, before, or since.

However, during this period, our positive relationship with medical professionals highlighted a serious need, not only with children, but with adults of all ages too. Hospitals and surgeries seemed to be suffering a serious influx of patients suffering from asthma. This condition, in the main, was dealt with by the use of inhalers, sometimes referred to as puffers. Medication was delivered through these devices when a patient felt an attack coming on. Nevertheless, whilst a good number of patients could be dealt with in this manner, at this time, there seemed to be a significant spike in the number of patients suffering more serious respiratory conditions. We were therefore asked if we could step in to assist patients by providing them with nebulisers - machines that atomized medication into a fine mist that could be forcibly inhaled and absorbed to effect relief, for those gasping for breath and restoring them to relatively normal respiration.

Taking on board this new need, firstly, we had to check our charity constitution to see if we could entertain taking on such a request. Looking at the relevant paragraph that dealt with our remit, it reads :-

'The objects of the National Association shall be to relieve sickness by the provision of respiration monitors or other medical equipment to infants whose lives without such equipment would otherwise be at risk, and by the supply of general medical equipment to such infants and other persons who are sick, convalescent, disabled, or handicapped.'

Other persons who are sick, etc, gave us the ability to help people of all ages. So, finding we could, our next move was to look at the various nebulisers on the market and understand how they worked and the conditions they aimed to assist. From the outset, our priority, as with the respiration



The World Traveller nebuliser
offered a new freedom for asthmatics

monitors, was the portability of such devices. Our aim wasn't just to provide this necessary medical equipment, but to improve the quality of life for those requiring such equipment. Many of these patients suffering from these acute conditions were confined to their house, not only because of their illness, but also needing to be around electricity connections to power the nebuliser.

Our research found the best equipment to use was a World Traveller, made quite locally to Northampton by a company called Medix, this was a great help as we could call into their works for advice and repair, should it become necessary. By definition, we found this machine to do exactly what we wanted. It could be powered by mains connection at home, ironically, by plugging into a cigarette lighter in a car, or by its own rechargeable internal power pack. So, it was truly portable, it could be used in the UK, or in Europe as it had flexible voltage input. The compressor was strong enough to deal with the thickest of medications through the nebuliser itself. There was just one drawback, it was quite heavy to carry, although, after using it for a long period of time, we found only those who were very elderly and quite frail, or those suffering from brittle asthma, were affected - these patients were minimal in comparison to those who benefited from the equipment. Another asset in using these machines was that they could be easily maintained, and sterilised, by qualified repairers, should they break down, allaying the fear of any cross contamination too.

One of the first nebuliser patients was an elderly lady who lived on the outskirts of Manchester, just off the M62. She had suffered for many years with COPD, or chronic obstructive pulmonary disease, which an 'umbrella' title for a group of diseases that cause airflow blockage and breathing-related problems, including emphysema and chronic bronchitis. It can be extremely debilitating, as it was in this case. The lady had been virtually housebound for almost thirteen years to this point, she felt like a prisoner in her own home - defined by her condition. When we first evaluated the nebulisers NARA would use, we looked at portability, this was to allow patients to have more freedom and offered them a quality of life too many of us take for granted. Just over a week after we'd delivered the lady with the equipment, she said she'd been able to go out for the first time on a bus trip. She was overjoyed; she felt her life had been given back to her. Indeed, she said she'd booked a few more similar trips. It was as though a new world and future had been opened up for her. Our decision to help those with nebulisers was certainly vindicated and paying dividends to those we helped.

1994 - 2004

By the end of 1994, we were, more or less, back up to strength and running to near normal speed. Thankfully the trustee had recovered, and work began from our new, and still current, office at Moulton Park Business Centre, Northampton. It was at this time that we were constantly asked what NARA stood for, when we explained, it left many confused, so we adopted the title, NARA - The Breathing Charity, which was immediately registered with the Charity Commission. We've had no issues since we've used this title.

From the outset of our appeal, we had decided to build up a good rapport with hospitals, surgeries and healthcare professionals. The tangible part of what we do is the provision of medical equipment, but just as important is the support we give to parents and families affected during the time they have our equipment. Having a good relationship with doctors and nurses has helped us provide effective support, and not simply paying lip service. Part of that support too, includes a 24-hour help-line, which our patients have come to rely on, when there's something wrong with their equipment. This support was something we knew we had to have in place from day one and is still in place today.

Our 'approachable' ethos revolved around experiences from the founding parents and increased as the number of patients we'd helped grew too. Where there is illness in any family it doesn't just affect the patient, but others too, be they siblings, or close and wider family members and carers too. From the outset we wanted to foster a feeling, with those we were helping, that they were part of a wider family. Each family had gone through similar problems and experiences, so could exchange views with us, and if they wished, others we were helping too. Most of the equipment we loaned out was taken out by hand, this was to ensure full and proper instruction could be given in how to use it properly.

We'd helped a mother, Marina, with a monitor for her baby, AJ, a few years previous. The monitor was required due to apnoea episodes. Once, AJ had grown much stronger and obviously older, the respiration monitor was no longer required and returned to us. Soon after we'd moved to our new office, Marina contacted us to ask if we could help with a further monitor for her new baby, Curtis, as she'd become quite anxious, and her GP felt it would allay any feeling of anxiety. Again, she kept the monitor for a while until baby Curtis had grown stronger and her anxiety had diminished. In the meantime, both Marina, and her sister, were diagnosed with asthma and both needed nebulisers, which, after the relevant GP's authority was given, were provided. Once Curtis had started nursery school, Marina came to help out at the charity office. A few years later, she and the family moved to Lincolnshire. In 2008, Marina called again, she was expecting another baby and needed to loan a respiration monitor, due to the family history of apnoea and her respiratory issues too. Her GP approved the loan for her new baby Marty, who again kept it until he was older and stronger. We kept in touch and some years



Above - Marina with baby Curtis
Below - Curtis today





AJ with his two children
Barnaby and Flora

later, AJ had got married and his wife was expecting their first child, Barnaby. Again, due to family respiratory problems, he applied to loan a monitor, which we provided; as we did to his daughter, Flora born a while after. It's good to know from simply helping with baby AJ, in the first instance, we've continued helping the family, into the next generation.

Our next patient we highlight is an elderly lady, Mrs B, from the West Midlands. Well into her seventies, she suffered from severe asthma and other respiratory conditions, that had impacted her life for a number of years. We provided her with a nebuliser, which helped her immensely.





Top - Mr & Mrs B with their winning ticket
Below - Mr & Mrs B on their holiday

Around that time, we were organising a raffle to raise funds for the charity, first prize was a four country Alpine tour. Mrs B and her husband purchased tickets and asked for more to sell to family and friends. When the draw was made it was Mr and Mrs B, who'd been drawn out as the winners of the first prize. When we contacted them to pass on the good news, they asked if the prize could be transferred to their son and daughter-in-law, as they hadn't got passports, and they felt too old to go. Two days later, we visited them to take the winning prize over and to check on her nebuliser. We were told, their son had insisted that they get passports and go on the trip. They did and thoroughly enjoyed themselves, especially Mrs B, who said her breathing had improved immeasurably during her stay in the Alps - the air was much cleaner and fresher than in the West Midlands. Sadly, twelve months after the trip Mrs B passed away, and within a few months Mr B also passed.

Death was something we had learned to become used to, especially dealing with more elderly patients, particularly those with severe respiratory problems. In the case of Mr and Mrs B, we trust that our intervention, not only assisted Mrs B by providing her with the medical equipment she needed, but their trip to the Alps was a high point in the latter years of their lives. They gave us a photo of them enjoying their time near, Neuschwanstein Castle, in Bavaria, Southern Germany - see photos in previous paragraph.

2004 - 2014

One thing we have learned over the course of many years, is how some patients, particularly children, who have severe respiratory conditions to contend with, push themselves and achieve much, despite their illness, which takes us to a young boy, Tommy, from Somerset, who lived with his grandmother. A nebuliser was applied for, due to a change of medication required, and our loaning him the equipment was approved by his GP. Tommy was a keen musician and had a dream of performing professionally upon leaving school. As the years went by, we learned that Tommy, not only refused to allow his condition to dominate his life, but found singing was actually helping him control his asthma.





Top - Tommy on stage performing
Below - His band with members of NARA

About ten years after we had initially loaned Tommy his nebuliser, we were invited to attend one of his band's concerts. It was a superb evening, and we were amazed how Tommy had well and truly got the better of his health issues. He told us that, "Singing has become one of my exercises to combat asthma."

One of our long-term patients, Indira, a lady in her sixties living in the Staffordshire, came to us suffering from bronchiectasis, a condition the NHS say, 'is where the airways of the lungs become widened, leading to a build-up of excess mucus that can make the lungs more vulnerable to infection' and fibrosis, or scarring of the lungs. Her conditions meant we had to provide her with more specialised equipment, in addition to a more 'run of the mill' machine. This was because, from time to time, when her breathing became impaired, and significantly worsened, her medication needed to be administered sonically, meaning it would take less effort for her to ingest, as compared to a normal nebuliser. It also gave her the freedom to lead a reasonably 'normal' life. This lady has been with us for ten years now, and she sincerely thanks us for our assistance and support.

Another elderly lady, Marion, from Hampshire, who is sadly no longer with us, applied for a nebuliser due to her suffering from severe asthma, which required relevant medication as prescribed by her GP. As her only income was her pension, she lived on limited funds but was so very grateful for our help she insisted on sending us £5 every week, she said, *"It's my way of saying 'thank you' for all your help. While I can give it, please accept it to help your wonderful charity."* Age and her condition got the better of her and she passed away peacefully in 2013.

Another patient was a new baby, Stanley, from Yorkshire, who needed help firstly with a respiration monitor, which the family had obtained separately from the hospital. However, his condition required a more specialised piece of equipment, an oxygen concentrator - a device that concentrates the



Stanley who needed a
portable oxygen concentrator

oxygen from the ambient air by selectively removing nitrogen to supply an oxygen-enriched product gas stream. They are used as medical devices for oxygen therapy in healthcare applications, especially where liquid or pressurized oxygen is too dangerous or inconvenient, such as in the home. The NHS could not provide, or source this equipment, so turned to NARA. This portable equipment for Stanley was to enable him and his family to take a holiday. Like a number of patients, we had never met prior to this but communicated on our social media site. It was an absolute pleasure to meet up with him and all his family.

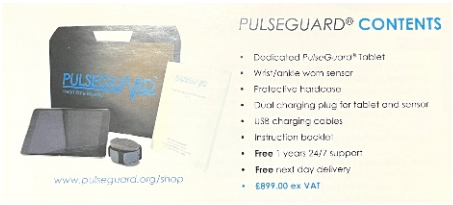


Stanley needed a Pulseguard
The sensor is attached to his wrist

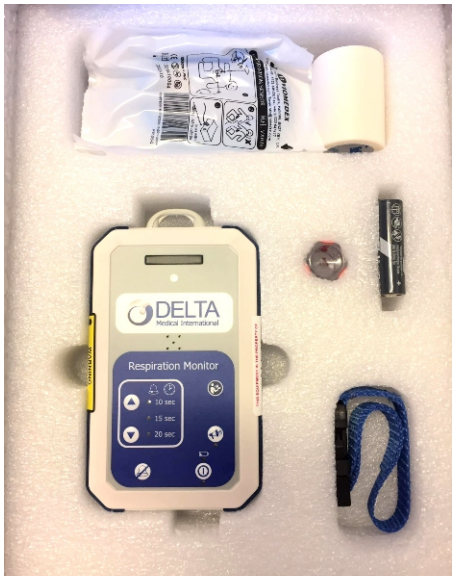
In the coming years, due to his condition, he became one of the first of our patients to use a Pulseguard – see below.

2014 - 2024

During this period our 'go to' respiration monitor, the Graseby MR10, was to be unfortunately discontinued. The manufacturer's had given us the regulatory five-year notice. It was quite a devastating blow, we'd been on the ground floor with this technology, almost from its birth in the early 1980s. Indeed, we had become a resource for the manufacturer when they considered updating and improving the monitors, which saw around four upgrades over 30 years. We were not too sure what we could do to replace the machines; they were our absolute staple. So, a programme was put into place to source a suitable replacement – much easier said than done. Most respiration monitors were used in special care baby units, not in the home. Home devices, which didn't come under the term 'medical equipment' were almost 'ten-a-penny' from High Street retailers, but not good enough in our eyes to fill the void made by the loss of the MR10. These home devices were not challenged by the stringent rules that medical equipment comes under, indeed we've always felt these to be almost 'gimmicks' rather than a valid apnoea alarm. Most other respiration monitors were good to use in static situations, where babies were in cots or confined receptacles, but not for every day use in the home where baby would be in a pram or carry cot in the back of a car. Almost at the end of this five-year period, we came across a company, Delta, that was developing a similar monitor to the MR10. Unfortunately, undergoing rigorous rules, so the new monitor, which could be termed as medical equipment, meant delay, after delay, whilst the manufacturers dealt with the seemingly endless trials, red tape and bureaucracy – not just in the UK, but under EU regulations too.



The Pulseguard



The Delta monitor has now replaced Graseby MR10

Even though Brexit had happened, rules on medical equipment were still under Europe's legislation. In the meantime, we'd seen a completely new development, using modern electronic technologies, both for sensing a baby's breathing and recording various levels by using a monitor called a Pulseguard, which could operate as an MR10, but in addition gave readings of heart rate and blood oxygen levels too. It was much more expensive than the MR10, but the only device we felt comfortable using, until Delta's monitor was accredited. The Pulseguard, and its new incarnation has been a great asset to use, particularly with older children and those with more complex respiratory issues. Toward the end of this financial period, the Delta monitor was up and running and we were using them – a god send, working as well as the MR10.

We helped another family with a baby, Kaiah, this time from London, as she'd suffered apnoea attacks. This request proved how this condition affected not only, the baby and her parents, but the whole family. Her



Baby Kaiah with her monitor

mother was so grateful for our help, she wrote to us saying, *'I have a child who suffers from apnoea (stops breathing). She was only two weeks old when we found out that she had apnoea, and this has changed the whole family`s way of life. I would like to say charities like NARA are a great help - if it wasn`t for charities like NARA a lot of people would be left helpless. So, if you can please do, (help them) you`re not just helping a child, you`re helping a child`s family to have as near as possible normal life.'*

Another aspect of support we were asked to provide was palliative care, for those at the end of their life, no matter of their age, who wish to spend their last days close to their family and those dear to them, at home rather than in hospital. We had a patient from Cambridgeshire, John, who was in his early



Palliative Care
Dignity in their last days

fifties, he's been diagnosed with a terminal condition, but needed a nebuliser to return home for his last days. We did this during the pandemic, but not whilst the restrictions were in place. We gave the equipment to John's wife on the Friday evening, he was due to come home on the Saturday morning. On the Monday morning, we had a call from the family to say that John had passed just a few short hours after he'd arrived home. He'd used the nebuliser a couple of times, and he was so very thankful that his final breath was taken within his own surroundings. His wife later told us we'd provided a short, but very necessary service for John and the extended family. The family generously raised funds for us, to go towards more nebulisers for similar patients and their families.

Forty-year summary

Summing up the last forty years, although it's somewhat of a cliche, we have seen our initial appeal grow 'from a little acorn to a big

oak tree'. Over the years we've been able to provide many thousands of patients with medical equipment and support, not only to them, but extending to their families too. We've given advice to many more thousands too. We can see the positive difference our charity has made during this time to so many lives. With regard to the monitors, countless parents have told us their baby would have died without our intervening in providing a respiration monitor. Those who have had nebulisers supplied by our charity have said their quality of life has significantly improved since using our equipment. Indeed, very recently, Mr P, from Northamptonshire, whose elderly wife has severe breathing difficulties, amongst a catalogue of other health issues, said, *"Thank you for providing the nebuliser, I know it's the reason my wife is still here, without it I would have lost her months ago."* It's so very satisfying to know our charity has worked very hard, over the past forty years, making a significant difference to many lives. Nonetheless, as we've mentioned in many reports previously, we couldn't have achieved anything without financial support from you, the British public, who we can only give our collective applause and sincere thanks.

Currently

And so, to this financial year, which we performed pretty much the same as in previous years. However, with a tough economic landscape, particularly toward the end of the year, we began finding it increasingly more difficult raise the same amount of funds as in previous years. So, we're pleased to exceed our expectations as regards income.

With that in mind, and due to the same reason, we found more people asking for our help, in as much as those who would either have been catered for by the NHS or afford to purchase equipment themselves. So, toward the end of our financial year, with the necessary extra workload in both areas to cope with these situations, the Trustees asked our paid member of staff to increase their hours of work, which from the beginning of March 2024 they agreed. Whilst more expensive, we're sure this extra help will pay dividends on all fronts in the coming months.

During this year we have provided medical equipment to over 300 new patients, as well as providing continued help and support to our 1,200 plus long term patients too. Long term patients are those we help for three years or more, they wouldn't necessarily include babies on monitors, who have their equipment for no more than two years – except in exceptional circumstances, nor would it include many of our palliative patients either.

Typical of the patients we helped during this period were a baby, Cassian, living with his parents in the Midlands, and another lady, Pravina, who was referred to us by her Respiratory Unit.



Cassian having a cuddle
Suffered from GORD

Cassian's parents approached us as he'd been quite poorly and had made several visits to their local A&E to find he was suffering from gastro-oesophageal reflux disease (GORD), which is a common condition, where acid from the stomach leaks up into the oesophagus, or gullet. It usually occurs as a result of the ring of muscle at the bottom of the oesophagus becoming weakened. It causes symptoms such as heartburn and an unpleasant taste in the back of the mouth. It may just be an occasional nuisance for some people, but for others it can be severe. In Cassian's case doctors were concerned it may induce apnoea attacks, and he'd stop breathing. A respiration monitor was approved for him to use during this difficult period, which was thought to be temporary and may improve with as he developed with age. We provided a monitor and to date, it's been a terrific reassurance to his worried and anxious parents. Indeed, his parents had this to say, *"Thank you so much, I don't know what we would have done without your help. If anyone wants a new charity to donate to, donate to NARA, they are literally saving lives every day."*

On the nebuliser side of things, a typical patient was Pravina, an elderly lady with an unusual condition. She applied for a nebuliser as she suffers, interstitial lung disease (ILD) – which the NHS describe as, 'a term for a group of conditions that cause inflammation and scarring in your lungs. Symptoms of ILD include shortness of breath and a dry cough. ILD can be caused by medication, radiation therapy, connective tissue diseases or inhaling harmful substances. Lung damage caused by ILD is often irreversible.'



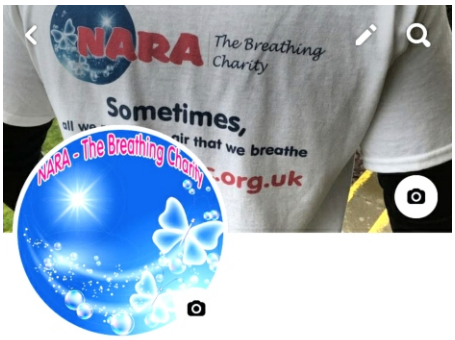
Pravina with her nebuliser attached

Although she has only been with us a short time, she has needed special care and attention and has been visited by our support team regularly since having the equipment.

Finally, we leave you with a word from a daughter whose mum wanted to spend her last days at home. Her request came like this, *"Good morning, I have been provided with your information by the hospital to contact with regards to obtain a nebuliser for my mum. She has end stage COPD, Lung Cancer and is being treated for a current pulmonary embolism and chest infection. Mum is adamant that she wishes to die at home and doctors are happy that she is currently stable enough to get home but would like her to have a nebuliser at home, which the hospital is no longer able to provide."* That was on June 23, 2023. We delivered her nebuliser by hand, but just a couple of days later we received this message, *"Good morning, I`d like to say a big Thank you for arranging and delivering a nebuliser for my mum. Mum passed away peacefully this morning as per her wishes with her family all around her. Thank you so much"* R L, June 28, 2023. A very short loan of equipment, but very necessary for this mum's dignified passing

As can be seen above, now, we're not restricted, as the past two years with Covid lockdowns, we're able to get out and about in the community once again and visit those needing our help. In total we made 407 visits to patients, which was very satisfying and rewarding, nevertheless, next year we want to increase that work if possible.

We took well over 2,500 calls, many needing and receiving tangible help and others simply wanting advice. And spent almost 1,500 hours on social media liasing with patients, their families and a good number of healthcare professionals too.



NARA - The Breathing Charity

One of our social media sites

These are just a few of the typical requests we've had during this year:-

"Hello, I have just spoken with one of your colleagues about the provision of a Nebuliser

for a patient I have under my care who would benefit from the use of a nebuliser. This lady has lung cancer and is also currently recovering from a viral infection and her cough, breathing and secretions are difficult but were helped considerably in hospital with a nebuliser. This lady has now been discharged home without a nebuliser and is struggling."

We provided the necessary nebuliser and received the following message.

"Thank you for organising provision of the equipment she needs, which I really appreciate, Thank you very much." – from a Palliative Physiotherapist (June 2023)

Another request, *"Dear colleagues, please can you help? We have a patient who has a 'trachy' (a tracheotomy - a procedure where a hole is made at the front of the neck. A tube is inserted through the opening and into the windpipe (trachea) to help you breathe.) He is in need of a new Nebuliser mask for his Trachy, his current mask is deteriorating."* Many Thanks from a Respiratory Nurse Specialist (September 2023)

Lastly, this request for 'end of life' care, *"Hi, I was wondering if you may consider sending a Nebuliser Compressor to one of our palliative patients? Your details were given to me by my Respiratory colleague. Many Thanks."* - Respiratory Nurse (October 2023)

And we constantly receive messages of thanks, such as:-

"Parents in the situation we were in or worse are out there, needing help, needing equipment, the NHS, is pushed financially to its limits and charities such as NARA are becoming vital."

"This lady and her team are amazing they work so hard; they loaned us a monitor for our grandson as his father stopped breathing as a baby and I had to resuscitate him. He has also been diagnosed with a genetic heart condition that is very hard to spot in babies. NARA is always available to talk to and we are so grateful, thank goodness our grandson is 2 now xx."

"Cannot Thank you enough for all the love and support we continue to get from NARA I can now sleep easy and know my baby is safe - if anything isn`t right his machine lets us know - his health is very up and down but we know if in doubt we can always call on you guys."

"Without NARA I literally don`t know where we would have turned. The NHS doesn`t fund medical grade apnoea monitors for children like J. Without NARA I dread to think what could have happened. They are there for us - a lifeline and we Thank you for every penny you donate to them."

Financial

Overall, despite the quite bleak economic horizon, we raised more money this year than we did in the previous year. Although we could be described as a small hand-in-mouth charity, our aim each year is to try and raise £100,000 for our projected funding. Exceeding is great, under achieving, would cause pressure, but not severe as we operate within our means. We believe this year's success goes hand in hand with the lifting of all restrictions that were put on individuals and businesses due to the Covid pandemic. As we've mentioned in a previous report, it was like coming out of the darkness into the light.

However, we're not too sure that increase is sustainable in the next year, particularly with an election due, anytime between the summer and Christmas. As we've seen over a number of years, an election, with a possible change of government, can cause an air of caution and uncertainty on the fiscal front.

Whatever the future holds, we at NARA, believe that with our minimal financial obligations, and outgoings, i.e. low administrative costs and commitments, feel we will be in a very positive position whatever the outcome.

Over the years, we've always be able to spend at the very least 80 pence in every £1 on the main objectives of the charity - in fact, in many years, it has been significantly above that. This year, we raised £123,074, spending £108,691 on our main objectives giving an outcome of 88 pence for every £1 raised.

Our total expenditure on the main objectives included purchasing hundreds of pieces of new equipment, including a full spectrum of different nebulisers – both mains and portable, apnoea monitors and other specialised equipment, together with all necessary disposable spares and accessories. We also had to dispose of 45 pieces of equipment from our stock, due to age, fair wear and tear - some nebulisers run up to six times a day, 7 days a week – and includes a number of others, which were taken out of service due to the possibility of cross contamination. We take no chances.

Each patient, together with other members of their family, is offered our support, that means being there for them when things go wrong, or they feel they need someone to talk to. As previously mentioned, our work also includes supporting many long-term patients too, so, for a small charity our outreach is far and wide.



We'd like to take this opportunity to say thank you to a number of supporters, companies who have been with us for thirty years, or more, including, the Morelli Group in London, Jacks Transport in Leicester, and Ludlow Motors in Ludlow. Thanks too to the following Trusts, the **Eric Tolson Charitable Trust, The Gilander Foundation, The Tula Trust** and **The Strangward Trust.**

We would also like to express our thanks to **The Sporting Bears** and **Kimbolton Country Fayre** for their continued financial support too - they've helped now for almost ten years.





There are many more who deserve thanks, but in the main, they wish to remain anonymous, so we respect their wishes.

Conclusion

Forty years is a long time, and we've seen our charity grow, mature, and develop within the current needs and requirements of the day, and positively touching countless lives, of all ages, across the length and breadth of our country. Many times, those enquiring for help, especially when they first contact us, are at their wits end, feeling deep in the depths of despair. Our aim is to support them through whatever difficulties they have, ensuring we can help them within the confines of our charity guidelines. One thing is for sure, we do not let the race, creed, or colour of anyone requesting our help, influence any decision we arrive at, nor does their sexuality, or social standing come into question either. We're here to help all we can. As you can see from the body of our report, it's always to try to improve our patient's, and indeed their family's, quality of life. Helping to release them from the bonds their illness restricts them to. In the main, we have succeeded, but as you've read, on a few occasions things can, very sadly, conclude in the opposite direction.

Initially, we only dealt with babies and small children, but as our charity has evolved it has embraced all ages, from those at the very start of their lives, to those in their twilight years. Due to this we've had to accept death as a fundamental process of life, but we trust our intervention, assistance and

provision of medical equipment has gone some way to make their last days more bearable.

In the past ten years too, by helping those needing palliative care, we have helped a number of those, close to the end of live, leave this world around family, rather than on a hospital ward. In the recent COVID years, we helped many stay clear of hospital, especially when infection rates were at their peak.

Our work has also kept us at the forefront of assessing new technology and medical equipment available to support those affected by chronic respiratory ailments. We believe, in the main, we have been able to select the most appropriate equipment for the patient's needs. Our support package also ensures that should a patient's requirements change, then alternative, or additional equipment can be supplied.

As we enter our fifth decade, we feel we are as relevant today as we were when we first began, if not more so, given firstly, the help now given to patients of all ages, from birth to advancing years. And, secondly, the role we played during the Covid years, and indeed since. We have become the 'go to' charity for many hospitals, especially respiratory units in many parts of the country. We believe our sustainability has passed many obstacles over the past forty years, and significantly tested throughout the past five years, especially with the pressures and rigours of the pandemic, which saw our charity stretched on a number of fronts, both financially and as an effective body offering help, not only to individuals in a period of crisis, but as a credible support to the NHS in their hour of need too. Yes, we were really pushed, but survived, which the Trustees are proud to have achieved. So, it's onwards and upwards to our Golden Anniversary in 2034.



THE PROCESS OF HELPING OUR PATIENTS



Prospective patients read what we offer either through our website, or reading our information leaflet, or via their GP or health professional





We're then contacted by phone, Email, or letter. Our staff take full details to determine how and if we can help.





Once we agree on a course of action, we ask the GP or healthcare professional responsible for the patient to sign an authorisation form. Once complete we can pack the equipment ready to deliver





Delivery of the equipment is usually via courier, Royal Mail, or our own representatives. We offer a 24 hour helpline to assist patients set up and enable them to keep their equipment in good working order







Once the equipment is received, our patients are called regularly to ensure all is working well









NARA The Breathing Charity
Registered Charity 327033

FINANICIAL YEAR ENDING 30th APRIL 2024

NARA - Annual Charity Accounts

NARA - The Breathing Charity, Moulton Park Business Centre, Redhouse Road, NORTHAMPTON, NN3 6AQ
Phone: 01604 494960 - Fax: 01604 497550 - Website: naratbc.org.uk - Email: info@thebreathingcharity.org.uk
Registered Charity 327033





Caring for all generations

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Charity Information

Trustees	A Jiggle E Atkins K Jiggle
Charity Number	327033
Charity Offices	Moulton Park Business Centre Redhouse Road Moulton Park Northampton NN3 6AQ
Examiner	Paul Connolly, FCCA. The Tax Shop Group Ltd G14, Moulton Park Business Centre Redhouse Road Moulton Park Northampton NN3 6AQ
Bankers	Barclays Bank Plc 267 Wellingborough Road Northampton NN1 4YD

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Independent Examiner's Report

Report to the trustees	**National Association for the Relief of Apnoea**
On accounts for the year ended	**30th April 2024**
Charity number	**327033**
Set out on pages	**Pages 3 to 6 inclusive.**
Responsibilities and basis of report	I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 30/04/2024. As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act"). I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.
Independent examiner's statement	I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect: - the accounting records were not kept in accordance with section 130 of the Charities Act; or - the accounts did not accord with the accounting records; or - the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination. I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.
Signed:	P. Connolly — **Date:** **05/02/25**
Name:	**Paul Connolly, FCCA.**
Relevant professional qualification(s) or body	**The Association of Chartered Certified Accountants**
Address	G14, Moulton Park Business Centre, Redhouse Road, Northampton, NN3 6AQ.

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Statement of Financial Activities for the Year Ended 30 April 2024

Incoming Resources	**Notes**	**2024 (£)**	**2023 (£)**
Donations from Grants, Trusts, Companies and Individuals	**2**	123,074	111,008
Direct Charitable Expenditure			
Medical Equipment care and support		108,691	84,576
Other Expenditure			
Fundraising Costs		2,563	2,694
Management and Administration of the Charity	**3**	14,100	12,229
Total Expenditure		125,355	99,499
Loss on value of monitors			
Expenditure after exceptional costs		125,355	99,499
Net Movement in Funds for the Year		(2,281)	11,509
Total Funds Brought Forward		39,248	27,739
Total Funds Carried Forward		36,967	39,248

There were no recognised gains or losses for 2024 other than those included in the Statement of Financial Activities.

The notes on pages 5 and 6 form part of these accounts

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Balance Sheet as at 30 April 2024

	Notes	2024 (£)	2023 (£)
Fixed Assets		36,119	30,094
Current Assets			
Cash at Bank and In Hand		7,193	9,574
Current Liabilities	**5**	(320)	(420)
Total Assets less Current Liabilities		42,992	39,248
Capital			
Unrestricted Funds		42,992	39,248
Total Funds Carried Forward			

Approved by the trustees on 23rd Feb 25 and signed on their behalf

Trustee

The notes on pages 5 and 6 form part of these accounts

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Notes to the Accounts

1 Accounting Policies

1.1 Basis of Preparation of Accounts

The accounts are prepared under the historical cost convention and include the results of the charity's operations which are described in the Trustees' Report and all of which are continuing.

The accounts have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014

The charity has taken advantage of the exemption in Financial Reporting Standard 102 (FRS 102) from the requirement to produce a cash flow statement on the grounds that it qualifies as a small charity.

1.2 Income

Voluntary income and donations are accounted for as received by the charity. The income from fundraising ventures is included gross, with the associated costs included in fundraising costs. No permanent endowments have been received in the period.

1.3 Value Added Tax

Value Added Tax is not recoverable by the charity, and as such is included in the relevant costs in the Statement of Financial Activities.

1.4 Fundraising Costs

Fundraising expenditure comprises costs incurred in inducing people and organisations to contribute financially to the charity's work. This includes the cost of advertising for donations and the staging of special fundraising events.

1.5 Management and Administration Expenditure

Expenditure on management and administration of the charity includes all expenditure not directly related to the charitable activity or fundraising ventures.

Notes to the Accounts (continued)

2. Income	2024 (£)	2023 (£)
From Covid Savings Fund	0	500
Donations	122,854	109,893
Medical contribution	220	615
Total	123,074	111,008

3. Administration Expenditure	2024 (£)	2023 (£)
Office Rent and Services	8,880	7,221
Administration staff	4,800	4,588
Independent Examination	420	420
Total	14,100	12,229

4. Staff Costs

No remuneration was paid to trustees in the year, nor were any trustees' expenses reimbursed. The staff costs were:

	2024 (£)	2023 (£)
Wages and Salaries	4,800	4,588

The average weekly number of staff employed by the charity during the year was as follows:

	2024 (£)	2023 (£)
Administrative	1	1

5. Current Liabilities	2024 (£)	2023 (£)
Accrual	320	420

THE NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA GENERALLY KNOWN AS HELP PREVEN

England & Wales - Charity number 327033

Accounts



NARA The Breathing Charity
Registered Charity 327033

FINANICIAL YEAR ENDING 30th APRIL 2023

NARA - Annual Charity Report

NARA - The Breathing Charity, Moulton Park Business Centre, Redhouse Road, NORTHAMPTON, NN3 6AQ
Phone: 01604 494960 - Fax: 01604 497550 - Website: naratbc.org.uk - Email: info@thebreathingcharity.org.uk
Registered Charity 327033

NARA Annual Report - 1st May 2022 to 30th April 2023



Following on from the previous two years blighted by Covid lockdowns and restrictions, we entered our new financial year in May 2022 with fresh hope, energy and optimism that the world would return to a relative normality. However, at that time, with war in Ukraine following Russia's invasion, a new struggle was underway and again on a global basis. The war saw an already pandemic battered world, now suffering shortages of fuel and food culminating in the prospect of a financial crisis on the horizon that would affect each and everyone of us, the UK being no exception. Increased fuel costs inevitably saw everyday living expenses rise on a weekly basis, so whilst free of the affects of a global pandemic, we, like many others, had new challenges ahead. Charities like ours rely on the generosity of others, with financial belts being tightened across the board, we knew we'd have another difficult year, but had to soldier through. We had responsibilities to those we were helping to ensure our care for them continued unhindered, we also knew they'd be an increased influx of others wishing to draw on our services in the weeks and months ahead.

It's at times like these when we look around and realise that many of those who suffer on a daily basis wear the greatest smiles. If we thought we were having a bad day, some of our patients face daily challenges, but almost always with a smile. So, it was no time for us to be glum, but to take inspiration from some of those we help whose lives are compromised by their condition and health each and every hour of the day.

At times like these, perhaps we could consider the lyrics of a song attributed to the late great Charlie Chaplin, and sung by Nat King Cole, simply called Smile. It's worth reminding you of them here,





Smile though your heart is aching
Smile even though it's breaking
When there are clouds in the sky, you'll get by
If you smile through your fear and sorrow
Smile and maybe tomorrow
You'll see the sun come shining through for you
Light up your face with gladness
Hide every trace of sadness
Although a tear may be ever so near
That's the time you must keep on trying
Smile, what's the use of crying?
You'll find that life is still worthwhile
If you just smile
That's the time you must keep on trying
Smile, what's the use of crying?
You'll find that life is still worthwhile
If you just smile

Over the life of the charity we have seen many others whose plight and fight for life has been simply amazing. They try to make the best of every day and every minute of every day. Living a life dictated to you by debilitating medical conditions, or severe disabilities rather than depressing them seems to simply spur them on through their individual adversities. Ruth lives by the mantra, quoted by American historian Alice Morse Earle, 'Every day may not be good, but there's something good in every day.'

During the course of this financial year we have helped many patients of all ages, with varying respiratory conditions across all regions of the UK. Here are just a few examples.

As mentioned above, we have a number of patients in our care who suffer life limiting conditions, however, despite this, on many occasions they smile through their pain. Indeed, visit any children's ward in any hospital and you'll see that despite their health issues many of these children have the brightest of smiles. It's this action, through the plight of their pain we draw inspiration to do the things we do to help them through their difficulties.

One of our most inspirational patients is a young lady called Ruth. She has given us permission to share her story with you. So, in her own words, here it is:-



'Hey, There! I'm Ruth. I am 29 years old and I live life to the absolute fullest with fun challenges, adventures, many projects on the go and very importantly a bucket list to complete. I want to share my love, passion, and happiness with the world but beyond that positivity, I also work hard on showing the raw, real reality of trying to live life to the full whilst also living with EDS (Ehlers-Danlos Syndrome) and other multiple chronic illnesses, which together for me are life-threatening and ultimately are shortening my life. But that will not stop me and if anything, it just makes me want to grab life and all opportunities I can even more.'

Ruth contributes to her vlog through various social media channels. Posting on her site 'Just Keep Swimming with Ruth and Willow (her dog). She introduces the site as, 'Making every moment count with my family, friends and incredible assistance dog Willow by my side. Follow me through the highs, lows and everything in between and when you start to struggle just remember to.. #Justkeepswimming, or alternatively she suggests #andifyoucantswimjustfloat

This post she sent out in April 2023 is typical of her courage,

'The golden hour really does make the difference between life and death.

The last 13 days since I've updated on here I wish I could say has been because I've been busy living but unfortunately I've been busy trying to stay alive.



The good thing?

I survived.

This is how one infection can spread, turn to sepsis and into septic shock. (I unfortunately have underlying complications which make me a huge risk for infections).

But sepsis can be and is fatal. I'm so lucky to be alive right now and I'm trying not to cry with help doing this but please don't take any moment for granted.

I love you all so much. (Yes I'm a soppy so and so and I always will be! #sorrynotsorry)

To you all, thank you, you know who you are and I can't explain just the difference your ongoing support it makes and means. Things are far from perfect and this is what makes my ongoing care and treatments so incredibly complicated.

But the main aim is to get me back home and get back some quality time and quality of life back into me (though it is really hard knowing the focus is changing) and most importantly to us as a family to make memories, (non medical ones).

But right now after 13 very long days (not all I can recall, and there isn't many photos because, too be Frank we were too busy trying to keep me alive) and I'm just so grateful to be stable as it really was touch and go at points, yes I should be used to it by now as I live knowing I'm living on limited time but still, it never gets any easier knowing any day could be your last and knowing my parents have to watch that is heartbreaking. Mum didn't leave my side, didn't sleep for days but the teams including ICU and critical care, surgeons and

anaesthetists and all the wonderful nurses saved me, saved us, a miracle or not I don't know I just know I'm lucky to be alive and writing this.

Just from me, hug your loved ones a little tighter tonight.

Any questions on sepsis or septic shock just ask or comment below, if I can just raise a little awareness through my story then I will always endeavour to, turning something negitive into positive, finding a way your story can help others, we can ALL make an impact, we can all make a little difference. I may not be here for the longest time but I'm definitely here to make the most of what I do have time.

But for now, rest, breathe and rest.

Thank you again for staying by our side. I love you all, so much.

All our love, Ruth, Chris, and Willow of course.'

We are delighted to announce that Ruth has been nominated for the 'Positive Role Model Award for Disablity' in the 2023 National Diversity Awards - something that we feel is fully deserved for her tireless work in helping others deal and come to terms with their disability, despite her dealing with her own on going issues.

Unfortunately, during this financial year we lost two tiny lives, which whilst painful for us, was much more acute for their immediate families and friends.

The first of these was a little boy affectionately known as JamJam, born with Patau's syndrome, or Trisomy 13.



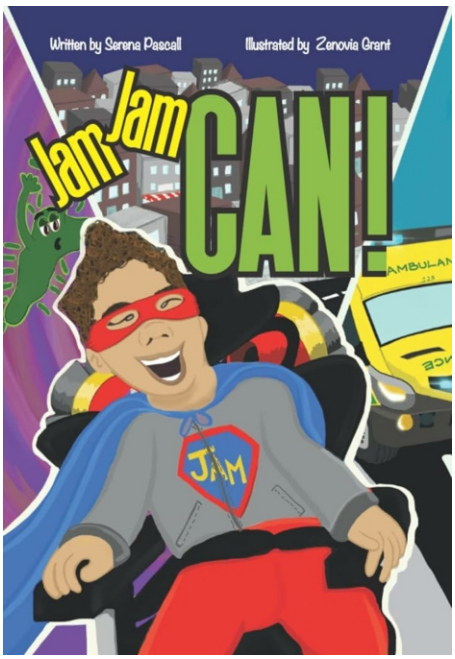
The condition is described on the NHS website as follows,

Patau's syndrome is a serious, rare genetic disorder caused by having an additional copy of chromosome 13 in some or all of the body's cells. It's also called trisomy 13. Each cell normally contains 23 pairs of chromosomes, which carry the genes you inherit from your parents. But a baby with Patau's syndrome has three copies of chromosome 13, instead of two. This severely disrupts normal development and, in many cases, results in miscarriage, stillbirth or the baby dying shortly after birth.Babies with Patau's syndrome grow slowly in the womb and have a low birth weight, along with a number of other serious medical problems. Patau's syndrome affects about 1 in every 4,000 births. The risk of having a baby with the syndrome increases with the mother's age. More than nine out of ten children born with Patau's syndrome die during the first year.

Born in January 2018, from the outset his parents were told that their precious new baby had a severe life limiting condition. NARA became involved with the family after their baby boy had stopped breathing and needed a respiration monitor so they could be made aware if he did it again. The day after delivery we received the following message, 'You guys saved my son's life last night. I cannot believe how your timing was impeccable and made the difference.' Messages like this, that we have received many times in the past, boost out resolve and confirm our actions are making a difference.

As we got to know him and his mother it was clear this little boy was special. Told that her baby would probably not survive pregnancy, after being born the prognosis for Jam Jam was that he'd not live to see his first birthday. He was also born with six fingers, six toes, and was deaf. Also, there was no tangible evidence of eyes, due to an untreatable condition called bilateral anophthalmia. So, his parents were told there was apparently no way that he'd ever have sight. Imagine the elation of his parents when at eight months old he opened his eyelid exposing a black marble - doctors were astounded he had limited sight. His mother described that day as a miracle.

Sadly, despite his continuing feats that defied the odds, in March 2023 his condition



and complex needs overwhelmed him. Nevertheless, although he died just weeks after his fifth birthday, his life was not only an inspiration to all those he came in contact with, but on a broader global basis through a book his mother wrote called, 'Jam Jam Can' about the highs and lows of living with a child with severe disabilities.

One of the reviewers of the book encompassed Jam Jam's life story,

'A refreshing read and I enjoyed the book and the happy life the little boy with special needs lives despite his disabilities. I recommend this storybook JamJam Can to all mainstream and special needs creche, preschool and nursery/schools across the continents. It is all inclusive and supports diversity as it portrays the main character JamJam as a coloured child. It is nice to see something different in a children's book and I give kudos to the writer who is a mum of a little lovely boy with disability.'



The second little boy, Isaac, was born in 2021 with heart defects, so his life was, again like Jam Jam, compromised from birth. At just four days old he had an operation and in the days that followed he had another to try and repair a hole in his heart. Quite early on, Isaac's doctor felt he needed an apnoea alarm,



so we stepped in to help by providing the necessary medical equipment and support. Throughout his short life his parents saw that he was a brave little fighter, but sadly neither that, nor the medical treatment he received to resolve the heart defects was enough to save him. He sadly died in 2022 aged just 18 months.

Moving on from our theme, throughout the year our charity provides medical equipment and support throughout the length and breadth of the UK, we also provide a 24hr

helpline for those who are experiencing difficulty with their equipment, those needing help from us for the first time, others simply needing advice,or those who are at a low ebb and feeling vulnerable with their condition and just need someone to talk to. Whatever their issues we are there to help, by providing them with the help and care they need, signposting them to the most appropriate agency for help, or providing that listening ear.

Our helpline is a physical telephone number, or many seek support through our social media platforms, which are seen as vital resources by our patients, their families and carers, particularly when they feel vulnerable.

The social media platforms offer a communication streams, not only with members of our charity team, but also with our patients who share similar conditions. This interaction offers them an additional gateway of support.

Of course, where possible, now that Covid restrictions had been lifted, we resumed our visit to patients ensuring their equipment is up to date and working efficiently, also that it's appropriate for their particular condition.

During this financial year those visits equate to around 400, that's in the region of around eight per week and with many, many miles of travel. During this financial year we had in excess of 1,200 patients, so meeting around a third of them in just one year is something we're very proud of. It's certainly appreciated by our patients.

At this point in previous reports, we have given examples of help given to those with with severe respiratory complex conditions and syndromes needing our help, together with the various pieces of equipment, ie; respiration monitors, nebulisers, and other equipment we've supplied to them, authorised by their healthcare professional. This time we feel it would be better to sub-divide help given to particular categories of people, ie; children and young people and adults and seniors.

Children and Young Adults



Our first example is 2 month old baby Bonnie, who suffers apnoea - cessation of breathing - episodes. This patient represents the original founding of the charity, helping those parents with children who simply forget to breathe. After the usual permissions were granted by the child's GP, we provided the parents with a respiration monitor. This was in July 2022, since then the equipment has been an additional guardian keeping check on Bonnie's breathing and alarming should she stop.

15 year old Ella who has a rare genetic disorder is our next patient. She suffers Sanfillipo syndrome, which is explained by the Sanfillipo Foundation as, '*Sanfilippo Syndrome — also known as Mucopolysaccharidosis type III or MPS III — is a terminal, neurodegenerative rare disease. It causes children to lose all the skills they've gained, suffer seizures and movement disorders, experience pain and suffering, and then die, often before the second decade of life*.



It is estimated that Sanfilippo Syndrome affects 1 in every 70,000 births. However, the prevalence could be higher. The true number will only be known when Sanfilippo is included in newborn screening.'

Sadly, Ella is another example of those patients with life limiting conditions as our opening words explain. We provided her with a portable nebuliser, her mother was thrilled and sent this message to us, *"Ella's new portable nebuliser, what a good idea, I had no idea these even existed. This means that she can take it out with us, which is great if Ella starts to struggle with secretions."*

A young 20 year old man, Ditta, is in a similar position as Ella above, he has Canavan's Syndrome, which is described as follows; '*Canavan disease is a neurological disorder in which the brain degenerates into spongy tissue full of small fluid-filled spaces. It is caused by a mutation in the ASPA gene which makes an enzyme called aspartoacylase. This enzyme is primarily present in oligodendrocytes, contributes to the manufacture of myelin, and is responsible for breaking down (metabolizing) the brain chemical N-acetyl-L-aspartate or N-acetyl-L-aspartic acid. In Canavan disease, many oligodendrocytes do not mature and instead die, leaving nerve cell projections known as axons vulnerable and unable to properly function.*

Canavan disease causes progressive brain atrophy. There is no cure, nor is there a standard course of treatment. Treatment is symptomatic and supportive. The prognosis for Canavan disease is poor. Death usually occurs before age ten, although some children may survive into their teens and twenties.'

Our charity has provided Ditta with a nebuliser to help treat respiratory infections he deals with on a regular basis.

13 year old Archie has been a patient of ours for a good number of years now. We've



been providing long-term help with his various and complex needs. Contracting Covid simply added to his problems and he needed new mains and portable nebulisers and replacement specialised apnoea and tremor monitor. Since we've know him, Archie has shown he is a fighter and has achieved much in spite of having a serious operation and dealing with his various illnesses and conditions. He's has an infectious smile too.

Another of our long term patients is Sophie, who we've looked after for almost ten years now. She has requested we provide her with a home spirometer, which will offer her a basic level of screening that utilises bluetooth technology to connect directly to a smart phone. Users can record Peak Flow and FEV1 measurements in the comfort of their own home with the ability to send results electronically to their healthcare advisor. It is designed to be used as a self-monitoring tool for those with a respiratory condition and as a wellness product for the health conscious.

By using this new equipment, Sophie's consultant suggests she may benefit long term from new treatment. We are looking to get this item funded. We also provide Sophie, on a monthly basis, with infusion sets for the administration of her medication. Like Archie, she too has a very infectious smile, despite her many health issues.

Our next patient is a 28 year old young lady, Lydia, who has Allergic Broncho-pulmonary Aspergillosis . It is described as, '*a*

condition that causes the patient to develop an allergic response in the airways to Aspergillus spores or colonising Aspergillus moulds. ABPA is predominantly found in patients with treatment-resistant asthma (although this is not always the case) and cystic fibrosis, and manifests with transient and fleeting pulmonary opacities and bronchiectasis.

It is estimated to affect 2.5 – 5% of those people with bronchial asthma, which equates to 125,000 – 250,000 cases, though the number diagnosed is far lower. Much better diagnostics are needed! Diagnosis can be very slow, with some estimates giving an average of 10 years (and up to 20 years) between the first symptoms and final diagnosis, a claim which is certainly borne out by the comments of some existing ABPA patients.

Typically ABPA is predominantly associated with poorly controlled asthma but can also include excessive mucus production, mucous plugs, coughing, haemoptysis, bronchiectasis, low-grade fever, weight loss and malaise.'

Again, we have provided Lydia with a nebuliser to treat a number of her respiratory infections and conditions.

Another young lady, 25 year old Koya, suffers severe asthma. When she contacted us she was struggling to cope with her condition and asked if we could help in any way. Again, a nebuliser was sent to her. She sent us the following message of thanks, *"Thank you for everything! I honestly cant put into words how much I appreciate what you guys have done. Thank you so much for getting me the nebuliser - it came so quick! These past couple of weeks have been extra trying, feeling a if I'm running off half a lung - it's not been fun. Honestly, thank you so very much."*

A patient who needed a more sophisticated nebuliser, 20 year old Edward, suffers Leopard, or Noonan Syndrome. '*Noonan syndrome is caused by a fault in one of several genes. At least eight different faulty genes have been linked to the condition so far. In some cases, the faulty gene associated with Noonan syndrome is inherited from one of the child's parents. The parent with the faulty gene may or may not have obvious features of the condition themselves. Only one parent needs to carry the fault to pass it on and each child they have has a 50% chance of being born with the condition. In other cases, the condition is caused by a new genetic fault that isn't inherited from either parent. In these cases, the chance of the parents having another child with Noonan syndrome is very small. It's estimated that between 1 in 1,000 and 1 in 2,500 children are born with Noonan syndrome. It affects both sexes and all ethnic groups equally.'*

The nebuliser we provided cost around £1,000, but is only used in exceptional circumstances. It is the most efficient device for dispensing medication and antibiotics.

Our next patients are babies, the first is a mum who needed a monitor for one of her



children born sometime after she had tragically suffered the loss of a previous baby. Losing a baby is something that most of us can only imagine, but to those who are unfortunate to suffer such a loss, that loss is immeasurable. As we helped her successfully with his older sibling, she came back to us again when expecting baby Oakley who was born during the late summer of 2022.

The monitor has helped tremendously in reducing her anxiety and, of course, reassuring her that it would alarm should her baby stop breathing.

Baby Ava was also born premature, she was a poorly baby and had suffered apnoea episodes that needed monitoring. Whilst in hospital there is 24 hour care and support and qualified medical support. Removing your baby from that environment to simply being at home with nothing but mum, dad and



possibly other members of the family is quite daunting. The use of the monitor gives that positive click every time the baby takes a breath, also knowing it will alarm if baby forgets to breathe offers such reassurance. Again, a monitor was provided by us.

Lastly, baby Scarlet, born in early Spring 2023, suffered from a number of respiratory disorders including a floppy larynx when the aryepiglotic folds fall inwards resulting in noisy breathing (stridor), difficulty feeding and sometimes increased effort in breathing.

It is said, if babies with this problem manage to feed well and gain weight then no operation is necessary as it usually goes away without any treatment by the age of 18 months.



We provided Scarlet's parents with a respiration monitor, again to help should she stop breathing.

Many of those parents supplied with respiration monitors have said that without the monitor their baby would have stopped breathing and they would have been unable to intervene, meaning they'd have possibly lost their precious child.

Older People and Seniors

In this next group of people we highlight some of those older people whose life is blighted by severe respiratory illness and conditions. Many of them have suffered for many years, but as they have grown older their condition has worsened reducing their quality of life. It's restoring some of that quality to these patients that makes our work



so worthwhile on a daily basis.

We begin with 88 year old Pauline who found herself in hospital for 120 days suffering blood clots and severe asthma. On being discharged from hospital she was prescribed with long term antibiotics and needed a nebuliser to administer them. On being given the equipment her daughter wrote this note of thanks, *'Thank you for the delivery and demonstration of the nebuliser for my mother, it was good for her to meet you. Since using it she can say it brings her much relief. Thank you also for your help and support you've given my mother, it is appreciated.'*

Our next patient, 70 year old Christine, was referred to us by her Lung Function Clinic as a person in need of a nebuliser due to her



suffering from COPD, advanced asthma, and emphysema. At this point, it's worth mentioning that we work closely with a number of the UK's respiratory hospitals and their teams responsible for their patient's post hospital treatment. Again, a nebuliser was provided to support her ongoing treatment.

51 year old Caroline came to us in early Autumn of 2022. She suffers from a quite rare condition of tracheobronchomalacia, or TBM, which is described as; *'a condition where there is softening of the cartilage within the walls of your airways. It can affect different parts of your lungs, your windpipe, known as your trachea and your main airways that branch into your lungs, called your bronchi. The cartilage is responsible for keeping the airways open, allowing air to easily move in and out as you breathe.*

Breathing in is an active process where the muscles of your diaphragm and rib cage contract to open up space for air to come into



the lungs and then they relax which allows the breath out.

TBM means that the airways are floppy. When the muscles relax, the airways are unable to stay open fully and they partially close down making it more difficult for the air to move out.

If you have phlegm, known as sputum, this will also get stuck if the airways partially close as you breathe out. This will make it more difficult for you to clear the sputum.'

Caroline also suffers severe asthma, so requires a nebuliser to administer necessary medication. As you can see from her photo, she was a patient we delivered her equipment to her doorstep, but waited in the car for her to pick it up and we used a mobile phone to talk to her to set it up. This was done as a safety exercise for both patient and our staff.

71 year old Helen, is a victim of Covid and now suffers Long Covid, which has compromised much of her health including her breathing. Necessary medication has been prescribed for administration via a nebuliser to assist with her ongoing treatment.

We received this lovely note of thanks from her hospital consultant, *'Thank you for getting in touch, I'm very grateful to you for offering to help our patient. I am hoping that like for many other patients, NARA would be able to make a difference to this lady's life. Best wishes and thanks once again.'*

Just as we have helped some of our children and young adults on a long term basis, we have similarly helped some of our older patients for long periods too. It was our dealings with 62 year old Julie since 1999, that caused concern as she came to us in the wake of her having Covid, chronic asthma and suffering a stroke.

Covid has left many people vulnerable to a range of respiratory conditions that impede their quality of life. Again a nebuliser was provided to assist with her ongoing treatment.

66 year old David was another victim of Covid which left him in a coma. Once recovered from his coma he was left with pneumonia and COPD, these conditions had



a profound effect on his breathing. During this financial year David has been provided with two nebulisers - owing to his infirmity he dropped and broke the original machine, so a new one was given.

Cold and damp weather conditions during late Autumn can be just as difficult for severe asthma sufferers as the pollen in the height of summer. Asthma can be triggered by a



plethora of things that healthy people take very much for granted. 58 year old Nami was one such patient to be affected by the changing climate as a long term sufferer of bronchiectasis. Bronchiectasis is a long-term condition where the airways of the lungs become widened, leading to a build-up of excess mucus that can make the lungs more vulnerable to infection. A nebuliser was provided to give her long term treatment.

Our next patient, 62 year old Abida has been supported by us since 2010. The equipment we had previously provided her with was in need of replacement. Typical of similar patients she has suffered COPD and reduced lung function for a good number of years and relies heavily on the equipment and support provided by NARA.

Helped since 2012, 48 year old Paula who suffers brittle asthma, severe breathing problems, and diabetes also needed her equipment updating, as did 58 year old Numtal who has been helped by NARA since 2018. Numtal suffers severe asthma, active invasive sinusitis. The new equipment provided was essential to ensure her nebuliser therapy remains effective.

Kady is a 45 year old lady who has been on our books and given support since 2017, a long term sufferer of COPD and severe asthma has been provided with a wealth of equipment, both portable and mains nebuliser to assist to maintain her with a reasonable quality of health.

Quality of health is something the majority of us take for granted. During the Covid months, it came to the fore that we're probably more vulnerable to health issues than we thought. Many who suffer sever conditions tend to be isolated and become defined by their condition, 50 year old Tracey is one such patient we helped who suffers from anxiety and depression, which is bought on from her long term suffering from severe asthma, COPD and polymyalgia rheumatica.

Lastly, we deal with those who have come to the end of their life and simply want to be amongst family and take their last breath in the comfort of their own home and environment. Where this happens, NARA has stepped in on a number of occassions to ensure a patient's last wish can be granted.

This was the case with 88 year old Irene, who suffered severe COPD, heart failure and diabetes. In November 2022 we were asked to help with a nebuliser so that Irene could leave hospital and live at home for her last days - we agreed. Irene died just before Christmas, but she was surrounded by her family - just as she wished - before she passed away.

Financial

As we emerged from the Covid lockdowns and entered a year of financial uncertainty, this financial year saw us not only rekindling relationships with long term supporters, but venturing to pastures new for funding, which saw our total income rise to a shade under £10,000 on the last financial year.

In terms of expenditure, that was along the lines of previous years, with small rises across the board in both admin and fundraising. Having said that it still saw us spending 84 pence in every £1 raised on the main objectives of the charity, but given the financial landscape we felt it was prudent to hold on to a significant amount of monies to carry forward to the next year - £9,574, as opposed to just over £3,000 in the previous year. Keeping this money in hand helped us through a number of lean spells when income was not as forthcoming as the historical norm.

It's good to report this time that we can now begin to recycle equipment once again, ie use for more than one patient, once the original patient is finished using it. We had to stop this practice during the Covid months due to cross contamination. Now, we have procedures in place congruent with standard practices in the field of sterilisation of medical equipment for reuse. Had we not had this facility it would have proved extremely difficult to service the increase in patients during this period. This along with the purchase of new equipment has helped us cope with a significant increase of patients.

At this juncture we must extend our grateful thanks to each and everyone who has supported us, be they individuals, groups, businesses, or trusts. Indeed, each and every donor, whatever the size of their donation has helped us immensely to continue or work throughout this financial year - sincere thanks to you all.

We have a great donor base, many have been with use for a good number of years. We appreciate there are those who help who wish to remain anonymous, but of those who have allowed them to name them include the following.

Firstly, ***Best at Travel***, who have supported us for the past 29 years, once again offered their help once again. It's good to be able to count on regular supporters such as these, not that we take their help for granted, but it's the relationship that counts.

Next come two trusts, the first helps our work in Cambridgeshire - the ***Alan Boswell Charitable Trust***

ALAN BOSWELL GROUP

CHARITABLE TRUST

followed by ***Charlotte Marshall Charitable Trust*** for our patients in Sussex.

As we move forward towards our 40th Anniversary, financially speaking it would appear that we've truly weathered the storms and come out the other side in good health. In 2023/2024 we look to build on these foundations.

Summary

Whilst these past 12 months have seen us move back to a relative normality. There's no doubt that Covid, or the effect of the pandemic still plays a major part in our everyday life. There's a certain frailty still existing for many who suffer ill health, be they young or old. In our work we have seen the ravages of Covid, with many sufferers coming to us with related respiratory conditions, something they never had suffered prior to Covid.

Others have come to us with other health issues, which doctors are referring to as Long Covid, which is a new condition and still being studied. Recovery from Long Covid varies. Some symptoms can improve quickly and others last longer. The chances of having long-term symptoms does not seem to be linked to how ill you are when you first get Covid-19. People who had mild symptoms at first can still have long-term problems. Some of the symptoms include, extreme tiredness (fatigue), feeling short of breath, loss of smell, muscle aches, or a number of other problems. Whilst in the main these conditions are not exclusively respiratory, we have seen a tremendous growth in Covid related respiratory problems, hence an overall increase in new patients of almost 300 more.

Strangely, we also noticed that the periods of pandemic lockdowns have seen a significant downturn in premature births, some figure abounding at present suggest around 50,000 less. We are currently awaiting reports from various bodies to confirm these figures and explanations for this phenomena.

As mentioned previously, we were pleased to be able once again to pay regular visits to patients face to face rather than the remote ways we used during the height of the pandemic. In saying this, none of our team, voluntary or otherwise, ever find themselves on a one to one basis with any patient, be they considered vulnerable or not.

The patients we visit are always aware of their allotted day and time of appointment, so they can have other members of their families, or chaperones with them. When visiting patients, we always use appropriate PPE including face masks and coverings as deemed necessary.

Looking forward, 2024 marks our 40th Anniversary since our charity was founded, it doesn't seem possible. In those years we've seen our work build and evolve within the constraints of our constitution.

Our overriding purpose has been to increase the quality of life for our patients, their families and carers. More simply than that, our patients fundamental need, be they young or more senior, is to be able to take a breath.





THE PROCESS OF HELPING OUR PATIENTS



Prospective patients read what we offer either through our website, or reading our information leaflet, or via their GP or health professional





We're then contacted by phone, Email, or letter. Our staff take full details to determine how and if we can help.





Once we agree on a course of action, we ask the GP or healthcare professional responsible for the patient to sign an authorisation form. Once complete we can pack the equipment ready to deliver





Delivery of the equipment is usually via courier, Royal Mail, or our own representatives. We offer a 24 hour helpline to assist patients set up and enable them to keep their equipment in good working order







Once the equipment is received, our patients are called regularly to ensure all is working well







NARA The Breathing Charity
Registered Charity 327033

FINANICIAL YEAR ENDING 30th APRIL 2023

NARA - Annual Charity Accounts

NARA - The Breathing Charity, Moulton Park Business Centre, Redhouse Road, NORTHAMPTON, NN3 6AQ
Phone: 01604 494960 - Fax: 01604 497550 - Website: naratbc.org.uk - Email: info@thebreathingcharity.org.uk
Registered Charity 327033





Caring for all generations

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Charity Information

Trustees	A Jiggle E Atkins K Jiggle
Charity Number	327033
Charity Offices	Moulton Park Business Centre Redhouse Road Moulton Park Northampton NN3 6AQ
Examiner	Paul Connolly, FCCA. The Tax Shop Group Ltd G14, Moulton Park Business Centre Redhouse Road Moulton Park Northampton NN3 6AQ
Bankers	Barclays Bank Plc 267 Wellingborough Road Northampton NN1 4YD

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Independent Examiner's Report

Report to the trustees	**National Association for the Relief of Apnoea**
On accounts for the year ended	**30th April 2023**
Charity number	**327033**
Set out on pages	**Pages 3 to 6 inclusive.**
Responsibilities and basis of report	I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 30/04/2023. As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act"). I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.
Independent examiner's statement	I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect: - the accounting records were not kept in accordance with section 130 of the Charities Act; or - the accounts did not accord with the accounting records; or - the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination. I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.
Signed:	P. Connolly **Date:** **20/02/24**
Name:	**Paul Connolly, FCCA.**
Relevant professional qualification(s) or body	**The Association of Chartered Certified Accountants**
Address	G14, Moulton Park Business Centre, Redhouse Road, Northampton, NN3 6AQ.

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Statement of Financial Activities for the Year Ended 30 April 2023

Incoming Resources	**Notes**	**2023 (£)**	**2022 (£)**
Donations from Grants, Trusts, Companies and Individuals	**2**	111,008	101,218
Direct Charitable Expenditure			
Medical Equipment care and support		84,576	94,507
Other Expenditure			
Fundraising Costs		2,694	1,728
Management and Administration of the Charity	**3**	12,229	11,230
Total Expenditure		99,499	107,465
Loss on value of monitors			8,325
Expenditure after exceptional costs		99,499	115,790
Net Movement in Funds for the Year		11,509	(14,572)
Total Funds Brought Forward		27,739	42,311
Total Funds Carried Forward		39,248	27,739

There were no recognised gains or losses for 2023 other than those included in the Statement of Financial Activities.

The notes on pages 5 and 6 form part of these accounts

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Balance Sheet as at 30 April 2023

	Notes	2023 (£)	2022 (£)
Fixed Assets		30,094	25,019
Current Assets			
Cash at Bank and In Hand		9,574	3,140
Current Liabilities	**5**	(420)	(420)
Total Assets less Current Liabilities		39,248	27,739
Capital			
Unrestricted Funds		39,248	27,739
Total Funds Carried Forward			

Approved by the trustees on 21st Feb 24 and signed on their behalf

Trustee

The notes on pages 5 and 6 form part of these accounts

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Notes to the Accounts

1 Accounting Policies

1.1 Basis of Preparation of Accounts

The accounts are prepared under the historical cost convention and include the results of the charity's operations which are described in the Trustees' Report and all of which are continuing.

The accounts have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014

The charity has taken advantage of the exemption in Financial Reporting Standard 102 (FRS 102) from the requirement to produce a cash flow statement on the grounds that it qualifies as a small charity.

1.2 Income

Voluntary income and donations are accounted for as received by the charity. The income from fundraising ventures is included gross, with the associated costs included in fundraising costs. No permanent endowments have been received in the period.

1.3 Value Added Tax

Value Added Tax is not recoverable by the charity, and as such is included in the relevant costs in the Statement of Financial Activities.

1.4 Fundraising Costs

Fundraising expenditure comprises costs incurred in inducing people and organisations to contribute financially to the charity's work. This includes the cost of advertising for donations and the staging of special fundraising events.

1.5 Management and Administration Expenditure

Expenditure on management and administration of the charity includes all expenditure not directly related to the charitable activity or fundraising ventures.

Notes to the Accounts (continued)

2. Income	**2023 (£)**	**2022 (£)**
From Covid Savings Fund	500	0
Donations	109,893	100,738
Medical contribution	615	480
Total	111,008	101,218

3. Administration Expenditure	**2023 (£)**	**2022 (£)**
Office Rent and Services	7,221	6,778
Administration staff	4,588	4,032
Independent Examination	420	420
Total	12,229	11,230

4. Staff Costs

No remuneration was paid to trustees in the year, nor were any trustees' expenses reimbursed. The staff costs were:

	2023 (£)	**2022 (£)**
Wages and Salaries	4,588	4,032

The average weekly number of staff employed by the charity during the year was as follows:

	2023	**2022**
Administrative	1	1

5. Current Liabilities	**2023 (£)**	**2022 (£)**
Accrual	420	420



NARA The Breathing Charity
Registered Charity 327033

FINANICIAL YEAR ENDING 30th APRIL 2023

NARA - Annual Charity Accounts

NARA - The Breathing Charity, Moulton Park Business Centre, Redhouse Road, NORTHAMPTON, NN3 6AQ
Phone: 01604 494960 - Fax: 01604 497550 - Website: naratbc.org.uk - Email: info@thebreathingcharity.org.uk
Registered Charity 327033





Caring for all generations

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Charity Information

Trustees	A Jiggle E Atkins K Jiggle
Charity Number	327033
Charity Offices	Moulton Park Business Centre Redhouse Road Moulton Park Northampton NN3 6AQ
Examiner	Paul Connolly, FCCA. The Tax Shop Group Ltd G14, Moulton Park Business Centre Redhouse Road Moulton Park Northampton NN3 6AQ
Bankers	Barclays Bank Plc 267 Wellingborough Road Northampton NN1 4YD

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Independent Examiner's Report

Report to the trustees	**National Association for the Relief of Apnoea**
On accounts for the year ended	**30th April 2023**
Charity number	**327033**
Set out on pages	**Pages 3 to 6 inclusive.**
Responsibilities and basis of report	I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 30/04/2023. As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act"). I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.
Independent examiner's statement	I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect: - the accounting records were not kept in accordance with section 130 of the Charities Act; or - the accounts did not accord with the accounting records; or - the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination. I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.
Signed:	P. Connolly **Date:** **20/02/24**
Name:	**Paul Connolly, FCCA.**
Relevant professional qualification(s) or body	**The Association of Chartered Certified Accountants**
Address	G14, Moulton Park Business Centre, Redhouse Road, Northampton, NN3 6AQ.

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Statement of Financial Activities for the Year Ended 30 April 2023

Incoming Resources	**Notes**	**2023 (£)**	**2022 (£)**
Donations from Grants, Trusts, Companies and Individuals	**2**	111,008	101,218
Direct Charitable Expenditure			
Medical Equipment care and support		84,576	94,507
Other Expenditure			
Fundraising Costs		2,694	1,728
Management and Administration of the Charity	**3**	12,229	11,230
Total Expenditure		99,499	107,465
Loss on value of monitors			8,325
Expenditure after exceptional costs		99,499	115,790
Net Movement in Funds for the Year		11,509	(14,572)
Total Funds Brought Forward		27,739	42,311
Total Funds Carried Forward		39,248	27,739

There were no recognised gains or losses for 2023 other than those included in the Statement of Financial Activities.

The notes on pages 5 and 6 form part of these accounts

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Balance Sheet as at 30 April 2023

	Notes	2023 (£)	2022 (£)
Fixed Assets		30,094	25,019
Current Assets			
Cash at Bank and In Hand		9,574	3,140
Current Liabilities	**5**	(420)	(420)
Total Assets less Current Liabilities		39,248	27,739
Capital			
Unrestricted Funds		39,248	27,739
Total Funds Carried Forward			

Approved by the trustees on 21st Feb 24 and signed on their behalf

Trustee

The notes on pages 5 and 6 form part of these accounts

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Notes to the Accounts

1 Accounting Policies

1.1 Basis of Preparation of Accounts

The accounts are prepared under the historical cost convention and include the results of the charity's operations which are described in the Trustees' Report and all of which are continuing.

The accounts have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014

The charity has taken advantage of the exemption in Financial Reporting Standard 102 (FRS 102) from the requirement to produce a cash flow statement on the grounds that it qualifies as a small charity.

1.2 Income

Voluntary income and donations are accounted for as received by the charity. The income from fundraising ventures is included gross, with the associated costs included in fundraising costs. No permanent endowments have been received in the period.

1.3 Value Added Tax

Value Added Tax is not recoverable by the charity, and as such is included in the relevant costs in the Statement of Financial Activities.

1.4 Fundraising Costs

Fundraising expenditure comprises costs incurred in inducing people and organisations to contribute financially to the charity's work. This includes the cost of advertising for donations and the staging of special fundraising events.

1.5 Management and Administration Expenditure

Expenditure on management and administration of the charity includes all expenditure not directly related to the charitable activity or fundraising ventures.

Notes to the Accounts (continued)

2. Income	**2023 (£)**	**2022 (£)**
From Covid Savings Fund	500	0
Donations	109,893	100,738
Medical contribution	615	480
Total	111,008	101,218

3. Administration Expenditure	**2023 (£)**	**2022 (£)**
Office Rent and Services	7,221	6,778
Administration staff	4,588	4,032
Independent Examination	420	420
Total	12,229	11,230

4. Staff Costs

No remuneration was paid to trustees in the year, nor were any trustees' expenses reimbursed. The staff costs were:

	2023 (£)	**2022 (£)**
Wages and Salaries	4,588	4,032

The average weekly number of staff employed by the charity during the year was as follows:

	2023	**2022**
Administrative	1	1

5. Current Liabilities	**2023 (£)**	**2022 (£)**
Accrual	420	420

THE NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA GENERALLY KNOWN AS HELP PREVEN

England & Wales - Charity number 327033

Accounts



NARA The Breathing Charity
Registered Charity 327033

FINANICIAL YEAR ENDING 30th APRIL 2022

NARA - Annual Charity Report

NARA - The Breathing Charity, Moulton Park Business Centre, Redhouse Road, NORTHAMPTON, NN3 6AQ
Phone: 01604 494960 - Fax: 01604 497550 - Website: naratbc.org.uk - Email: info@thebreathingcharity.org.uk
Registered Charity 327033

NARA Annual Report - 1st May 2021 to 30th April 2022



As our new financial year commenced, we were still under the social restriction of a second lockdown, due to the spread of the Covid-19 virus, which had blighted lives not simply on a national level, but on a global basis too. The UK government urged people to be patient ahead of the next planned relaxation of the rules mid-May. With the onset of a vaccination programme, and despite the further complication of a South African strain becoming rife, the 17th May saw restrictions relaxed allowing indoor hospitality to reopen with groups of up to six people. By the latter part of June, the government's latest initiative 'Grab a Jab' saw hundreds of venues, including stadiums, shopping centres and theatres, turned into temporary vaccination centres in order to increase the number of people receiving vaccinations. Then on 19th July, the final stage of Covid restrictions were lifted in England, allowing nightclubs to reopen and abolishing social distancing rules, and the wearing of face coverings was no longer required by law.

Against the background of the foregoing, our charity continued to battle through assisting those, already burdened with severe respiratory conditions who were considered one of the most vulnerable of people in the face of the virus. With such a widespread effect, it came as no surprise that some of those patients caught Covid, and became very poorly, some needed hospitalisation, sadly some didn't survive. Nevertheless, NARA played a significant role in keeping many of our patients, old and new, out of hospital and in the relative safety of their own home. We must admit, that the Covid pandemic put a strain on our charity, challenging and restricting the way we obtained and delivered equipment, supported patients, and generally functioned, but we feel with our almost forty-year experience, and thanks to those we have formed relationships with over the years, we rose and coped well with the demands of the situation. The fragile and unease of returning to a more 'normal' life, protected by immunisation, led many to become more confident with the passage of time. The biggest problem both for us and our patients was complacency, with many thinking it was now 'all over' rather than living beside the virus and its many strains. Again, we managed to pull through, as our headline suggests, by the end of the year we were 'still standing'.

Enough of us 'blowing our own trumpet', let's see what some of our patients said about us as we give an overview of just a handful of those assisted during the year.

Respiration Monitors

Whilst we were now using the new Delta monitor, the retirement of one of our suppliers saw us able to buy a good number of the older, but still working Graseby MR10 models at a very competitive and discounted price, which was a godsend, especially with our inability to hold or organise fundraising events.

This first case is very sad as the couple approached us some four years after very sadly losing their first daughter who suffered severe cystic fibrosis. The NHS website describes cystic fibrosis as follows, Cystic fibrosis as an inherited condition that causes sticky mucus to build up in the lungs and digestive system. This causes lung infections and problems with digesting food. In the UK, most cases of cystic fibrosis are picked up at birth using the newborn screening heel prick test. Symptoms usually start in early childhood and vary from child to child, but the condition gets slowly worse over time, with the lungs and digestive system becoming increasingly damaged. Treatments are available to help reduce the problems caused by the condition and make it easier to live with, but sadly life expectancy is shortened. After their second daughter, Baby P was born, tests revealed she too had inherited the condition. A monitor was required to check Little P's breathing, during a particularly testing period. Describing their daughter as their 'rainbow miracle' baby, they offered these words, "With the help of NARA we were given a machine to monitor her breathing and I used until I felt it was ok not to worry as much. Thank you so much to Ann and all the team".



Little P of North-West England

Now we look at a set of twin girls, from South-West England. During their first weeks of life, they developed a problem in that whenever they swallowed, they choked and occasionally stopped breathing altogether. Their worried and extremely anxious mother called us, and we helped by providing them with respiration monitors. Mum sent this message to us when the situation eased and the girls seemed to grow out of the problem, "We are so thankful for all of the help we were given from NARA - when you're at your most anxious and the babies are so little it was so lovely to have somebody listen and understand. They are now very healthy one-year-olds that are thriving in every way!"



Twin baby girls from the South-West

Another set of twins next, born at 28 weeks, from the North-West. Whilst one of the boys progressed well, the other gave doctors cause for concern in that he suffered haemothorax, this is where blood collects in the space between the chest wall and the lung, making it difficult for the baby to breathe. Affecting the lower section of the left lung a decision was made to remove part of the lung to relieve the problem. Whilst drastic and invasive it was the only way forward. The parents of the boy contacted us after it was recommended that they have a respiration monitor, post operation, just in case there were further issues. Thankfully, there were no more problems, and the young boy is





Twin boys from North-West
Top: Days old - Bottom: More recent

progressing well. The parents said, "we're delighted with the help we received from NARA."

The story of our next patient, five-week-old baby boy, O, from Greater London, is graphically described here by his mother. "Our son was only five weeks old when he suddenly stopped breathing. There was no noise, or choking sound to warn us, we just happened to look down and saw him turning blue in my



Baby O of Greater London

arms. Thankfully on that occasion we were able to resuscitate him. He had a recent diagnosis of a rare chromosome disorder and with many tests pending we were unsure what caused the incident or how likely it was to reoccur. The fear of being unable to protect him from another silent attack was paralyzing. I couldn't see how we would ever be able to sleep, drive, or manage the urgent demands of our potty-training toddler without taking our eyes off our boy. Thankfully NARA was able to loan us an apnoea monitor, which would sound an alarm if he stopped breathing. This gave us so much peace of mind and allowed us to build a much more normal family life together. We will be forever grateful for the loan of this life saving equipment."

We're pleased to say, despite his health problems O is progressing reasonably well.

Another of our very young patients, Baby I, from the South-West of England, had a problem with his internal organs too. In this case, it wasn't his lungs, but his heart and arteries. At just hours old, it was found that his blood wasn't circulating properly, and on



Baby I of South-West England

closer examination he was found to have a hole in his heart. At four days old, surgeons put bands around one artery to restrict the amount of blood flow going to his lungs to allow more blood flow to go to the rest of his body this was done via the chest, the surgery went well. The following day he had another operation, this time this surgery via his groin was to place a stent into his artery which usually closes soon after birth but was needed to continue working to keep his heart pumping. NARA was called upon for this brave and determined little lad to alert his parents should he stop breathing.

Advanced Monitoring

Regrettably, the pandemic not only took lives, but also hit the fabric of many businesses causing them to close their doors for good. Our supplier of advanced monitoring equipment PulseGuard were one such company. Over a handful of years, using latest technology they'd offered us a more sophisticated form of monitoring breathing, pulse, and heart rate together with added alarm should the baby suffer an apnoea episode- stop breathing. Not only did it monitor each and every function, but also provided professional healthcare workers with the necessary data logging of bodily activities. Their equipment was used by a number of our younger patients with great success, unlike the respiration monitors, this equipment could monitor patients of all ages. Sadly, the economic strain of the past two years became too much for the company to continue and they closed. Thankfully, members of their staff alerted us to another company that could not only take over running of our existing stock of equipment but introduced us to a new improved system they had developed. So, during the course of the year, we were able to transfer all our current patients over to the new system.

To give an example, we look at the case of a toddler, named J, from the West-Midlands, who we mentioned in our last report suffering from West's Syndrome, which is a constellation of symptoms characterized by epileptic/infantile spasms, abnormal brain wave patterns called hypsarrhythmia and



Toddler J of the West-Midlands

intellectual disability. Three-year-old J, had used one of the original PulseGuard monitors, then seamlessly transferred to one of the new units. Under the care of another agency, one of the nurses involved with the family commented, "Thank you for all your help with 'J', you've got no idea to the extent of the help you've given. Not only have you help a very sick boy, but you've helped mum enormously too." The boy's mum added, "the equipment has been our saviour, and I can't thank you enough as a mum to know my baby makes it through the night."

Nebulisers

Our 'bread and butter' work over the past twenty-five years has been the provision of nebulisers, which atomise medications so they may be administered with relevant ease. It's possibly the most vital piece of our patient's armour in their battle with their differing respiratory conditions.

Firstly, a young lady, A-C from Wales, who was recommended to us by one of our patients in Yorkshire. It's comforting to know our patients have so much confidence in us. Living under the care of a hospice for almost more than two-thirds her life, A-C suffers from a number of health conditions, caused by degenerative multi-function-disease. Much of her body is compromised by this condition including her breathing, she suffers severe



A-C of Wales

asthma and epilepsy too.

She required a nebuliser to administer various necessary doses of medications. After the usual authorisations from her healthcare professionals, we provided her with the equipment she required. Overjoyed with our help, she went on social media posting a film of her opening her new nebuliser, ending with the tag line, "thank you to the incredible NARA - The Breathing Charity".

We're often contacted by NHS Respiratory Community Teams from various regions of the UK to help their patients by the provision of a nebuliser. One such man helped was 63-year-old Mr N, who suffers from chronic obstructive pulmonary disease (COPD). The NHS website describes COPD as, 'the name for a group of lung conditions that cause breathing difficulties. The breathing problems tend to get gradually worse over time and can limit your normal activities, although treatment can help keep the condition under control.' Providing Mr N with a nebuliser allows him to remain within his home environment rather than being hospitalised.

Another patient recommended by a palliative nurse from another local respiratory team was a middle-aged lady of the traveller community. Her health issues included breathing difficulties, and a number of mental health problems. Being a member of the travellers' community led to her not necessarily having access to mains electricity. We therefore had to look for a good quality portable machine, which could be used or charged on the mains, or used via a battery. Once the equipment was delivered, the nurse made the following comment, 'Thank you so much again for everything you do, you go above and beyond to help our patients.'

Next up was a 57-year-old lady again from East Anglia, who suffers bouts of severe asthma, plus other health issues such as lupus, coronary heart disease, and depression was referred to us by the National Asthma Campaign as she needed a nebuliser and they do not provide equipment. We went through our usual channels and sought approval with her GP and we're able to help. She was absolutely delighted with our response, "I am so grateful for the help and support that I've had from this charity, following a bad bout of asthma. When I contacted them, I was desperate for help. I needed an up-to-date nebuliser, which I now have at home and has greatly improved my life, by making it so much more manageable. The help I've received has been excellent and the people from the charity are friendly and understanding. I would definitely recommend this charity to anyone in need."

We had another request for a specific piece of equipment, this time it was for a young seven-year-old boy, O, from South-West England. He suffered severe autism, complex health issues, global development delay, severe asthma and eczema. Due to his autism, noise from one of our usual nebulisers caused the lad more problems, so we had to provided him with a silent device, so medication could be administered without problems. His mum said, "O struggles with asthma and quick onset laboured breathing from allergies, he is mentally disabled and is mentally around the age of 11 months, so has no understanding of waiting in a hospital room for a nebuliser, So, NARA providing one that we could use in the comfort of our own home has been an absolute life saver. O also has autism and sensory processing disorder, and Ann went above and beyond when she found us a silent one that reduces stress and anxiety whilst using the much-needed piece of equipment. Thanks so much NARA. I have recommended you to the special school my son goes to."



Seven-year-old O of South-West England



Mr E of the East-Midlands



A-C of Wales and R of South-East England have become good friends

Lastly, from time to time we deal with people who have social and domestic issues, this was the case of 65-year-old Mr E of the East Midlands, who lived in sheltered accommodation. Also suffering from COPD, he needed a nebuliser to administer his medication. Not only was he, but the sheltered housing group also thanked us for our intervention and provision of equipment.

Other equipment

In more recent years we've provided infusion sets to those patients who need medication administered via a manual or automatic syringe pump. Again our patient, a young lady from Yorkshire, referred her good friend R to us to see if we could provide her with infusion sets. R, a young lady from South-East England, suffers Addison's Disease and Ehlers-Danlos syndrome are conditions which affect a number of vital organs, which in turn compromise many bodily functions including breathing.

Delighted that we were able to help her, R said, "I am so grateful to NARA and the work it does. It provides me monthly with vital medical equipment that I need and unfortunately falls through the gap between my hospital and GP. Without this I would have to pay for these things and when you have serious long term medical conditions there is so much you have to manage but with NARA's help, I can relax knowing I can get my medical equipment safely and regularly."

Financial

There's no doubt, over the past two financial years, like many other organisations, our charity has encountered some of the darkest months. Having to not only pare-back on some of our methods of supporting our patients, but fundraising events too. This in turn left us a little short of our overall income for the year, in relation to previous years. It would have been foolhardy to have expected any different.

However, thanks to some excellent relationships built up over almost forty years of our existence with a good number of our supporters, and being able to carry over almost £10,000 from 2020-2021, the blow was somewhat cushioned to what it could have been .

In relation to obtaining new equipment we were not only affected by the virus, but also the fall out of Brexit, which reduced the supply of equipment as new checks and systems were adopted when importing goods, leaving us to use new retailers and suppliers.

We were very fortunate to be offered some low-cost equipment, both nebulisers and respiration monitors by several retailers, plus we were given an ample supply of personal protective equipment (PPE), by another business working out of the same premises as we do.

Throughout the course of the financial year, like many similar charitable organisations we were offered loans to support us throughout the difficulties, but we declined any such assistance as accepting it would have meant us repaying whatever we had loaned and therefore compromising future finances. We felt it better to weather the storm, if we possibly could.

So, again, thankfully, with the cooperation of our suppliers, and the generosity of our supporters we were able to pull through.

At this juncture, although a good number wanted to remain anonymous, it's worth highlighting a couple of the many who donated to our cause.





A fun evening at the Empress Club, New Brighton raised £1,300

Firstly, special thanks to the grandmother of one of our patients, who in March 2022 raised £1,300, by organising a charity 'Rock Night' together with members of the Empress Club, New Brighton, in memory of her late friend.



Secondly, to Brayleys car dealership, who have supported our charity for a good number of years and have, according to their social media post, been proud to do so. It's building relationships with businesses like Brayleys that greatly assist our economic survival. Thank you.

T&C PRECISION LTD

Another company that has supported our charity for almost 30 years is T&C Precision Ltd, again it's working closely with companies such as theirs that offer long term financial stability to our small, but necessary charity.

The Gilbert Lane Trust

Lastly, but by no means least, the Gilbert Lane Trust, once again supported our work in Lincolnshire. We're truly grateful for their kind assistance, which is a life-line for our patients in that area.

Summary

As has been the theme of this report, thanks to our working with all those we come into contact with during the course of our work, be it patient, medical professional, supplier, or financial supporter our robustness has seen us through possibly the worse and darkest months since our founding. Together we have all done our bit, even going the extra mile, to achieve our goals, for which we are most grateful and thankful. Whilst the next twelve months will no doubt raise more issues, hopefully, these will not include any further restrictions due to the virus. Having said that, two of our number fell victim to the virus during the latter stages of the financial year and had to spend time isolating.

Again, during the lockdowns particularly we had to adopt new methods of delivering equipment and supporting patients. Our normal methods of delivering equipment, where we visit the patient, obviously had to be changed. Instead of actually going into their residence and showing them how to set the equipment up, we delivered it to the doorstep, return to our vehicle, call the patient and walk them through step-by-step in how to set up their equipment. Whilst not ideal, it was the best we could do under the circumstances. In certain instances, it did have a positive outcome as a number of them became more au-fait with what they were using, understanding how it worked. This was very useful, should they encounter difficulties at a later date.

Otherwise, if the foregoing wasn't possible, we gave the equipment to the patient's healthcare professional for them to set up, which worked well too. However, with healthcare professionals stretched to the limit dealing with the virus, it wasn't always possible.

Supporting patients too, in excess of 900, meant a different approach as we were not allowed any social contact for many months. The safety of those who work for us, be they trustees, staff, third party workers, or volunteers they had to be protected at all times. Telephone calls were an obvious means of contact, social media channels too, in certain cases we also used facilities like Skype, Zoom or FaceTime where we could communicate face to face via the internet.

In a nutshell, deliveries to their door were up from 164 to 243, telephone calls up by just over a third to 2,720, and hours spent on social media channels increased by almost a third to 2,645 hrs. There was also a significant increase in call from those concerned about their own breathing conditions, or that of a relative, or friend - up from last year's total to just under 2,500. This also included us signposting callers to other organisations which could help with other issues such as housing, financial problems, loneliness, and mental health problems. Calls of the latter nature became more frequent towards the end of our year, especially, with cost-of-living crisis looming, caused in the main by Russia's invasion of Ukraine, another global issue which no doubt will cause many national issues in the coming months ahead.

As we enter a new financial year, we do so, secure in the knowledge that we're still standing as we approach our fortieth year - a truly significant achievement. The main objective of our work within the charity is to offer those who suffer from very debilitating respiratory conditions with a quality of life we all too often take for granted. The lockdowns caused by the pandemic has gone someway to many understanding the loneliness that a good number of our patients endure on a daily basis.

The photo below is one of our patients experiencing the enormous joy of simply being free to enjoy nature; not confined, or defined by her condition. Sincere thanks to all who make this possible for those we help.



Over many years of providing medical equipment we've helped various people to re-engage and enjoy life once again. Some after much time of being isolated by their respiratory illnesses and conditions. Of course, there are those who wanted to purely do things most of us consider mundane, like going to school, going to the shops or just regaining their independence.



This couple were able to take a holiday after many years without due to illness. NARA's provision of a portable nebuliser made it possible for them to travel.



After being supplied with a nebuliser this couple were able to celebrate their wedding anniversary. Without NARA's help this would not have been possible



This lad needed help with a monitor from a very early age. With NARA's help he was able to start school along with his peers - something his parents never thought possible



Now a dad himself, we first helped the above man when he was just a schoolboy in need of a nebuliser. His dream was to become a singer in a band. Despite his condition his dream came true

THANK YOU FOR HELPING US HELP PEOPLE LIKE THEM



David Amess with his wife Julia
NARA's event at the Cafe Royal in 1987



Sir David Amess - 1952-2021

On 15th October, like most, we were staggered to learn of the tragic, mindless and unnecessary loss of Sir David Amess, MP, violently assassinated whilst serving his constituents at his surgery in Southend-on-Sea. His passing tore into the hearts of many at NARA as during our infancy, whilst then Member of Parliament for Basildon, we were introduced to him. His advice, support and encouragement did much to assist us during those embryonic days when we were laying the foundations of our now long-established charity. Our photo shows him and his wife, Julia, at the Cafe Royal in London, in October 1987, where after just three years of operation we celebrated assisting 300 worried parents and their babies by providing them with necessary respiration monitors. Unfortunately, with the passage of time, and with the pressures of his work, both in government and local responsibilities, we lost touch with Sir David, but never forgot the kindness shown by a most generous man. To Julia, his children, Katie, Sarah and David Jnr, together with his extended family and friends, all at NARA offer our deepest condolences and sympathy.

THE PROCESS OF HELPING OUR PATIENTS



Prospective patients read what we offer either through our website, or reading our information leaflet, or via their GP or health professional





We're then contacted by phone, Email, or letter. Our staff take full details to determine how and if we can help.





Once we agree on a course of action, we ask the GP or healthcare professional responsible for the patient to sign an authorisation form. Once complete we can pack the equipment ready to deliver





Delivery of the equipment is usually via courier, Royal Mail, or our own representatives. We offer a 24 hour helpline to assist patients set up and enable them to keep their equipment in good working order







Once the equipment is received, our patients are called regularly to ensure all is working well





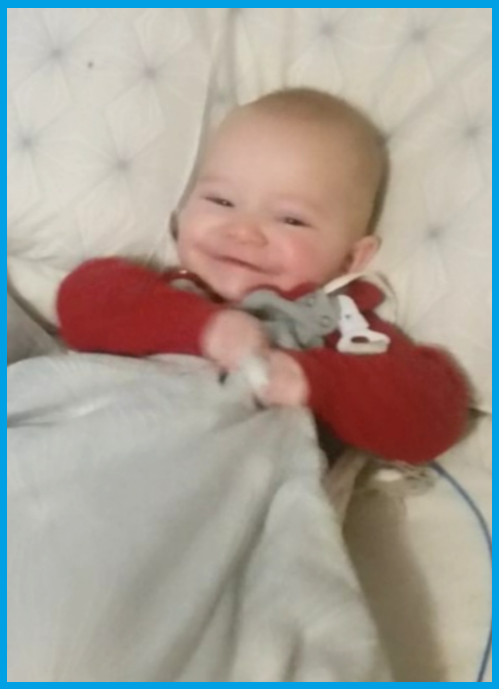


NARA The Breathing Charity
Registered Charity 327033

FINANICIAL YEAR ENDING 30th APRIL 2022

NARA - Annual Charity Accounts

NARA - The Breathing Charity, Moulton Park Business Centre, Redhouse Road, NORTHAMPTON, NN3 6AQ
Phone: 01604 494960 - Fax: 01604 497550 - Website: naratbc.org.uk - Email: info@thebreathingcharity.org.uk
Registered Charity 327033





Caring for all generations

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Charity Information

Trustees	A Jiggle E Atkins K Jiggle
Charity Number	327033
Charity Offices	Moulton Park Business Centre Redhouse Road Moulton Park Northampton NN3 6AQ
Examiner	Andrew Nottingham Taxwright 65 Moss Street Keith Banffshire AB55 5HE
Bankers	Barclays Bank Plc 267 Wellingborough Road Northampton NN1 4YD

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

I report on the accounts of the Trust for the year ended 30 April 2021 which are set out on pages 3 and 6

Respective Responsibilities of Trustees and Examiner

As the charity's trustees you are responsible for the preparation of the accounts: you consider that the audit requirement of Section 43(2) of the Charities Act 1993 (the Act) does not apply. It is my responsibility to state, on the basis of procedures specified in the General Directions given by the Charity Commissioners under Section 43(7)(b) of the Act, whether particular matters have come to my attention.

Basis of Independent Examiner's Report

My examination was carried out in accordance with the General Directions given by the Charity Commissioners. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently I do not express an audit opinion on the view given by the accounts.

Independent Examiner's Statement

In connection with my examination, no matter has come to my attention:

(1) which gives me reasonable cause to believe that in any material respect the requirements
- to keep accounting records in accordance with section 41 of the Act: and
- to prepare accounts which accord with the accounting records and to comply with the accounting requirements of the Act have not been met or

(2) to which in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.



A W Nottingham FCCA
Taxwright
65 Moss Street
Keith
Banffshire
AB55 5HE

Date 15/8/22

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Statement of Financial Activities
For the Year Ended 30 April 2022

	Notes	Unrestricted Funds 2022	Unrestricted Funds 2021
Incoming Resources			
Donations from Grants, Trusts, Companies and Individuals	2	101,218	121,425
Direct Charitable Expenditure			
Medical equipment care and support		94,507	100,691
Other Expenditure			
Fundraising costs		1,728	2,040
Management and Administration of the Charity	3	11,230	10,647
Total Expenditure		107,465	113,378
Loss in value of monitors		8,325	-
Expenditure after exceptional cost		115,790	113,378
Net Movement in Funds for the Year		(14,572)	8,047
Total Funds Brought Forward		42,311	34,264
Total Funds Carried Forward		27,739	42,311

There were no recognised gains or losses for 2022 other than those included in the Statement of Financial Activities.

The notes on pages 5 and 6 form part of these accounts

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Balance Sheet as at 30 April 2022

	Notes	2022	2021
		£	£
Fixed Assets		25,019	33,344
Current Assets			
Cash at Bank and In Hand		3,140	9,453
Current Liabilities	5	(420)	(486)
Total Assets less Current Liabilities		27,739	42,311
Capital			
Unrestricted Funds		27.739	42.311

Approved by the trustees on 29th January 23 and signed on their behalf

Trustee

The notes on pages 5 and 6 form part of these accounts

Notes to the Accounts

For the Year Ended 30 April 2021

1 Accounting Policies

1.1 Basis of Preparation of Accounts

The accounts are prepared under the historical cost convention and include the results of the charity's operations which are described in the Trustees' Report and all of which are continuing.

The accounts have been prepared in accordance with the Statement of Recommended Practice for charity accounts.

The charity has taken advantage of the exemption in Financial Reporting Standard No 1 from the requirement to produce a cashflow statement on the grounds that it qualifies as a small charity.

1.2 Income

Voluntary income and donations are accounted for as received by the charity. The income from fundraising ventures is included gross, with the associated costs included in fundraising costs. No permanent endowments have been received in the period.

1.3 Value Added Tax

Value Added Tax is not recoverable by the charity, and as such is included in the relevant costs in the Statement of Financial Activities.

1.4 Fundraising Costs

Fundraising expenditure comprises costs incurred in inducing people and organisations to contribute financially to the charity's work. This includes the cost of advertising for donations and the staging of special fundraising events.

1.5 Management and Administration Expenditure

Expenditure on management and administration of the charity includes all expenditure not directly related to the charitable activity or fundraising ventures. This includes costs of renting and running office premises, staff salaries for administrative staff and fees of an independent examination.

2. Income

	2022	2021
	£	£
Net transfer from savings	-	2,000
Donations	100,738	118,635
Medical Contributions	480	790
	101,218	121,425

3. Administration Expenditure

	2022	2021
	£	£
Office Rent and Services	6,778	6,081
Administration Staff	4,032	4,080
Independent Examination	420	486
	11,230	10,647

4. Staff Costs

No remuneration was paid to trustees in the year, nor were any trustees' expenses reimbursed. The staff costs were:

	2022	2021
	£	£
Wages and Salaries	4,032	4,080

The average weekly number of staff employed by the charity during the year was as follows:

	2022	2021
Administrative	1	1

5. Current Liabilities

	2022	2021
	£	£
Accrual	420	486

THE NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA GENERALLY KNOWN AS HELP PREVEN

England & Wales - Charity number 327033

Accounts



NARA The Breathing Charity
Registered Charity 327033

FINANICIAL YEAR ENDING
30th APRIL 2021

NARA - Annual Charity Report

NARA - The Breathing Charity, Moulton Park Business Centre, Redhouse Road, NORTHAMPTON, NN3 6AQ
Phone: 01604 494960 - Fax: 01604 497550 - Website: naratbc.org.uk - Email: info@thebreathingcharity.org.uk
Registered Charity 327033

NARA Annual Report - 1st May 2020 to 30th April 2021

Keeping Calm and Carrying On

Our new financial year began in the midst of the Covid pandemic, and lockdown in our country. According to government statistics infections were running at 10,000 new cases per day and testing capacity working flat out showing the biggest number in 24hrs with 122,347 provided over the previous 24 hours. Working toward a relaxation of lockdown restrictions the launch of a track and trace system was being rolled out. The UK government updated its coronavirus message from "stay at home, protect the NHS, save lives" to "stay alert, control the virus, save lives", with a number of plans afoot for a road back to a relative return to normality, led by the scientific analysis of the situation, being discussed. Our country, indeed, the world, was a very different place than it was just twelve months previously, and the challenges we as a charity faced, particularly as we assist with those suffering from severe respiratory conditions, were enormous. Nevertheless, this was not a time for blind panic, but working within government guidelines, providing the assistance and care to our patients we could and basically keeping calm and carrying on with our work.



One of the biggest challenges we were up against was the total cessation of face-to-face contact with our patients, but still delivering them with the comfort and care of our support. As mentioned in our last report, the reality of the pandemic, was that the public at large, subject to lockdown regulations, were now understanding something of the situation our patients had become accustomed too for most of their lives, which enabled some to fully appreciate the loneliness, isolation and psychological traumas many of our patients endure day-to-day. The virus impacted our patients in other ways too, with Covid patients naturally given priority at GP surgeries and hospitals usual appointments for other ailments were subjected to delays and cancellations. This had a knock-on effect as the burden and support of these patients descended on other organisations and charities such as ours.

As for the charity as a whole, with some businesses closed, or many people working from home, and the chaos of the pandemic purchasing medical equipment was far from easy. Naturally, as Covid is a respiratory virus, the NHS had purchased much of the stock of nebulisers for use within the hospitals and equipping the new temporary regional 'Nightingale' hospitals to cope with an influx of patients. Things would obviously be very different due to the pandemic, and from the start of 2021 those difficulties would be compounded by the effects of Brexit too, but we were up for one of the most demanding 12 months in our charity's almost 40-year history.

Monitors

Respiration Monitors

The good news to report in regard to respiration monitors during this year was the advent of the new Delta monitor, which finally gained the necessary approvals and certification to be release as a bone fide piece of medical equipment to be used to detect a baby's respiratory movements. Largely based upon the design and working of the now defunct Graseby MR10, it was something we looked forward to being available as a credible replacement for the former stalwart respiration monitor. Of course, we firstly had to trial the new monitor alongside the existing MR10 - the monitor we had complete confidence in using through the life of the charity. The first Delta monitors were delivered during the early month of the new financial year and parents of babies suffering from apnoea were only too pleased to assist trial the new equipment.

Parents of the first baby to receive a Delta monitor lived in Tyne & Wear, their son (baby R), one of twins, was born prematurely at 24 weeks, and suffered bouts of severe apnoea attacks. After finding our charity on the website, and with the relevant approvals from the child's doctor, the medical equipment was provided - both an MR10 and a Delta monitor. Whilst baby R suffered breathing difficulties, thankfully his twin brother was fine. Using both monitors in tandem for around six months, baby R's parents gave a positive report on the Delta monitor, saying they felt it 'far superior' than the MR10. This was great news for us indeed. Upon returning the monitors to us, and baby R now recovered, his mother messaged us the following, '*After worrying and struggling to get the equipment that my little boy needed, I came across NARA - The Breathing Charity where I spoke to a lovely lady who was so helpful and reassuring. The charity was literally a life saver I honestly can't thank them enough.*'



Baby R

The second baby assisted with the new Delta monitor was from Croydon, his mother had experienced a number of difficult births. This baby boy was born prematurely, so naturally the parents were very anxious for the safety of their new-born child, 'M'. His parents were very au fait with the charity as we were also helping, and still continue to help, his older baby sister who had been born very premature and suffers severe apnoea and respiratory issues. At the time of writing this report, whilst both babies are progressing reasonably well, they still need the monitors and NARA's support. From conversations with the parents, we learn the Delta monitor is performing very well.



Baby M and the new Delta monitor



Above: Baby M, Below: his sister



Another new baby helped with a respiration monitor was from Lincolnshire. Born to an older mum, baby I, a full-term baby, needed our assistance due to there being history of cot death in the family. Healthcare professionals felt it was entirely appropriate for the baby to be monitored during the initial months of her life. We're pleased to report that baby has progressed well with no health issues, the monitor was simply provided to reduce parental anxiety and offer reassurance.



Baby I from Lincolnshire

Of course, we had a good number of other children on monitors throughout this period who we continued to support, some only need support for a few months whilst others, who develop additional medical issues need more long-term assistance. For example, we first helped baby M, a little girl, from Hampshire, way back in 2015, initially due to prematurity. However, over the years, the child has developed a number of debilitating health issues concerning her breathing, which suggests a greater underlying issue - such as Ehlers-Danlos syndrome, which, to quote the National Library of Medicine, has the following respiratory issues, '*Persons with the Ehlers-Danlos syndromes (EDS) report a wide range of respiratory symptoms, most commonly shortness of breath, exercise limitation, and cough. Also reported are noisy breathing attributed to asthma, difficulty with deep inhalation, and inspiratory thoracic pain.*' We have learned from our experience that; EDS is an underlying condition associated with sleep apnoea. We have a number of patients with this condition. So, even though baby 'M' is now six her parents still rely on the respiration monitor to detect her breathing movements, especially at night.

Other children helped during this financial year include the following





- A baby girl from Cradley Heath suffering from numerous episodes of cessation of breathing and gastric reflux. Patient came to our attention following being admitted to hospital after being given CPR.

- A 13-week premature baby from Maidstone who suffered apnoea and gastric reflux episodes. Whilst in special care baby unit in hospital the baby was known to regularly choke on her own vomit.

- Another premature baby girl, born at 27-weeks, this time from Skegness, suffering apnoea episodes and needing oxygen.

- A baby girl from Birkenhead, the sibling of a cot death victim.

- A baby boy from Hertfordshire, one of twins, who was found to have abnormal lung tissue and suffering from kernicterus - a type of brain damage that can result from high levels of bilirubin in a baby's blood. It can cause athetoid cerebral palsy and hearing loss. Kernicterus also causes problems with vision and teeth and sometimes can cause intellectual disabilities.

- A baby girl from Blackpool suffering from cystic fibrosis, who had a stoma due to a blockage in her bowel. She had had another operation whilst still in the womb. Her parents had already lost a child due to cystic fibrosis.

- A four-year-old boy from Bradford, suffering from apnoea brought on by Wolff-Parkinson-White Syndrome - episodes of fast heartbeats seen in WPW syndrome usually aren't life-threatening, but serious heart problems can occur. Rarely, WPW syndrome may lead to sudden cardiac death in children and young adults.

During the course of the year, all patients were regularly contacted by phone, internet, or our social media sites to make sure all was well and patient's equipment working efficiently. Also, regular supplies of spares and accessories were sent out.

PulseGuard

In our last report we went into great detail of our using the PulseGuard monitor to assist a number of patients with respiratory complications, dwelling mostly on a little girl from Southampton with Retts Syndrome. This year, whilst we continue to help her and a number of others, we were presented with a three-year-old boy, named J from Warwickshire who had been diagnosed by healthcare professionals as suffering from floppy, unresponsive episodes of apnoea. So, initially we were asked to provide a respiration monitor, however, on talking further with the nurse we felt that the PulseGuard would be a better solution as there was a suggestion that the boy fitted on occasions. Agreeing to using the PulseGuard, after a few months, the data downloaded from the equipment by his doctor, suggested an additional diagnosis of the boy's condition. He was found to be suffering infantile spasms more commonly referred to as 'West's Syndrome'. Epilepsy Action describe infantile spasms as follows, '*Infantile spasms are a very specific type of seizure with a characteristic age of onset (a typical age when seizures start). They are nearly always accompanied by a very characteristic pattern on the electroencephalogram (EEG). This pattern is called 'hypsarrhythmia'. The combination of the infantile spasms, age of onset and EEG pattern defines the epilepsy syndrome called, 'West syndrome'. It is called this after Dr William West, who first described the condition in his 4-month-old son in 1841. West syndrome happens in about one in 2,500-3,000 children. This means that about 350-400 children will develop West syndrome in the UK each year.*' Of course, the PulseGuard is the ideal piece of equipment to use in this situation as it has a dual role of observing both the boy's breathing and fits. In this case, J is now in receipt of proper treatment for all his conditions, indeed, he has been able to attend nursery school.



Three year old J

During these initial stages of to the Covid-19 variant plaguing our nation and the wider world, keeping the risk of cross contamination was at the forefront of our thoughts. Therefore, we asked parents to hold onto monitors for a longer period of time than normal, this was so we could await the relevant government advice of how to clean equipment once it was returned, so it was completely safe to resend out as and when required.

Nebulisers

Consumed by Covid much highlight and attention has been given to respiratory conditions, both nationally and globally. Necessary equipment, including nebulisers, have been in short supply and we have encountered a number of difficulties in obtaining certain types and brand of nebulisers usually used by the charity. As previously mentioned, cross contamination has had to be at the forefront of our minds. Helping those with long-term health issues are not included in this as they need equipment full time, so it is rarely returned. However, short term loans, including palliative care for those patients needing equipment for a limited amount of time did need reassessing. It would be ludicrous us loaning expensive equipment just for a few weeks knowing, whilst Covid was still prevalent, we would possibly have to destroy it. We were able to identify a number of cheaper, but equally efficient nebulisers for shorter loans. However, where patients had contracted Covid-19 and needed our assistance with equipment, that equipment would have to be bagged up and retained by the patient's relatives until we received guidance on how to deal with it.

In many cases, the use of a nebuliser does not simply allow a patient to administer necessary medications but allows many to lead an independent life without constantly requiring GP appointments and Hospital admissions. With the NHS under tremendous pressure dealing with the enormity of Covid, we felt our work became more vital in trying to keep already vulnerable patients away from these hubs where the virus could be easily transmitted.

We start with a letter we received from the wife of a patient in Great Yarmouth, Norfolk. Although we made little mention of it in our last report, it does encompass the difficulties and struggles suffered by many of those we help. Working with him throughout this financial year we thought it may be useful to report what our help can do and how appreciative they are to both of us as a charity and all who donate to us.

'*Just wanted to write to you about how important a nebuliser is to my husband. My husband was diagnosed with tongue cancer 5 years ago, he underwent vigorous and intense radiotherapy and chemo which left him with a severe burnt mouth and tongue, so bad was the treatment it damaged his saliva glandes and stopped him being able to ever swallow again and stopped the movement of his tongue.*

Whilst it was great news that the cancer had gone, we never imagined what an impact on all our lives it would be. My husband can NEVER eat or drink again and he is fitted with a peg in his stomach, and it is attached to a machine that pumps a liquid prescription food into his stomach and water is pumped in him this way too. This has had a devastating impact on all of us now, I have to cook and eat in the kitchen on my own, no longer can go out for meals or stop and have lunch or a drink and we couldn't go out for a meal on our 41-year wedding anniversary. We all find it hard when the family come together for Sunday roast and especially Christmas dinner because my husband has to go in the bedroom because it is so hard for him to see the food and drinks knowing he cannot have any himself. It pains me with every mouthful I can taste and enjoy that this social and enjoyable thing we all do every day, my husband cannot join in and do anymore.

He also has to deal with all the saliva and mucus build up in his throat and this is where the nebuliser is a very important piece of equipment because it loosens the mucus and makes his mouth damp, this is so important to free this as it can go down on his lungs and cause pneumonia. Although my husband feels tethered to his peg and using the nebuliser four or five times per day, we all know how important this equipment is to him.

My husband and all of us are so very, very, grateful for donations that charities like NARA receive and the work they do is so appreciated because this helps people like my husband to continue to have some quality of life after cancer. We thank you all so very much for making his fight much easier.'

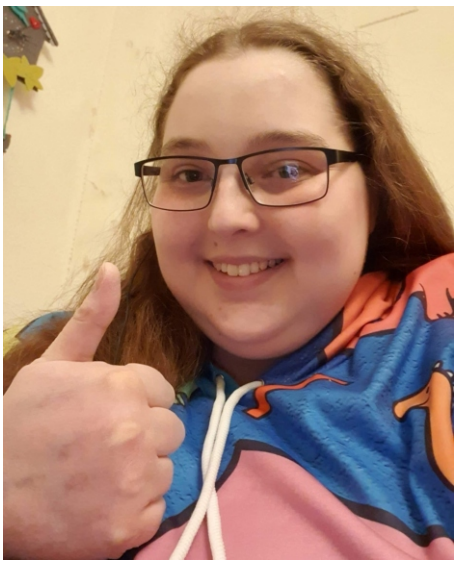
Despite the rigors of Covid, and those he suffers on a daily basis, this gentleman is in good spirits, and we continue to assist him month on month. The story of his daily battle to do many things we all take for granted inspired our small team even more to rise to the current challenges the pandemic has added to many of those who, due to other dreadful conditions, are now considered the most vulnerable sector of society.

Naturally, the Covid virus had significant impact on many of our patients as due to their vulnerability, despite having the regulation PPE, they didn't feel confident of going out to get regular exercise. A particular patient, a 27-year-old young lady, S, from Bradford, needed a specialised piece of exercise equipment to help build and keep her fitness levels to assist her breathing and her on-going health issues. Although not a usual purchase, we sourced a recumbent exercise bike for her and had it delivered to her home. Her words of thanks sum everything up very well.

'*I cannot thank you enough for getting this bike for me, I'm thrilled. I can't tell you how grateful I am. It allows me to get out of breath in a safe and controlled way which means I can work on building my fitness which is something I've not been able to do for a long time. And now, I can exercise meters away from nebuliser machines and steroid injections and where nobody will stare at me or ask me invasive questions about my medical devices and conditions. The ability to exercise regularly in a way that is safe for me is something that I know is going to have a huge impact on my quality of life. It gives me hope, an element of control, and will mean I can enjoy more things with my family without struggling to breathe. I'm just so happy. Thank-you again, so, so, much.*'







Another young lady, in her late teens, 'H', from Hampshire, an existing long-term patient of ours needed a more powerful and quieter nebuliser to administer necessary medication. As a college student and part-time worker, she needed something that drew minimal attention when in use. We provided her with a portable, sonic unit that more than adequately suited her needs. Again, a letter from her mother summed up her thanks.

'*Thank you so much to NARA - The Breathing Charity for the new stronger improved silent nebuliser for H, it will make an enormous difference to her life allowing her more independence and privacy without a noisy neb going on during classes at college and work. Everyone deserves the right to breathe.*'



H from Hampshire

We follow the above with a resume of just a few examples of those new patients helped during this financial year.





- A 73-year-old lady from Twickenham, suffering from COPD and Motor Neuron Disease.
- A 90-year-old lady from Coventry, suffering from severe asthma, recurrent chest infections and additionally curvature of the spine.
- A 71-year-old lady from Colchester suffering from COPD
- A profoundly deaf 85-year-old lady from Lincolnshire, suffering from Bronchiectasis - a disease in which there is permanent enlargement of parts of the airways of the lung. Symptoms typically include a chronic cough with mucus production. Other symptoms include shortness of breath, coughing up blood, and chest pain.
- An 84-year-old gentleman from Bradford suffering from COPD who struggles to talk due to the severity of his condition.
- Another from Bradford, a 74-year-old gentleman, suffering from lung fibrosis, or scarring of the lung.
- A 60-year-old gentleman from Ely referred to us by the James Padgett Brain Injury Rehabilitation Team, a stroke patient suffering from respiratory difficulties.
- A 96-year-old gentleman from Nottingham suffering from dementia and severe asthma.
- An 89-year-old gentleman from Cambridge, suffering COPD and dementia
- An 88-year-old lady from Waterlooville suffering from Covid-19 and COPD
- A 63-year-old gentleman from Nottingham suffering from emphysema
- A 65-year-old lady NHS worker from Coventry who contracted Covid-19, leaving her with long term damage to her lungs which severely affects her breathing
- A 65-year-old gentleman from Kent suffering Covid-19.
- A 33-year-old lady from Norfolk suffering from brittle asthma where her bouts of asthma worsen suddenly or severely.
- A 53-year-old gentleman from Cambridgeshire suffering Idiopathic Pulmonary Fibrosis a rare, progressive illness of the respiratory system, characterised by the thickening and stiffening of lung tissue, associated with the formation of scar tissue. It is a type of chronic scarring lung disease which leads to a progressive and irreversible decline in lung function.
- A 72-year-old gentleman from Swindon suffering COPD
- A 73-year-old lady from Denbighshire suffering from Bronchiectasis and COPD

During this financial year we kept up our support for those who needed palliative care. Those patients in the closing weeks, days and hours of their lives who wished to depart this world with dignity in their own environment, be it home, or care home, surrounded by close family and friends.

Support

Our work not only concerns the number of new patients we assist, but the ongoing support and assistance we offer to our list of long-term patients situated in the four corners of the UK, be they in England, Scotland, Wales, or Northern Ireland.

Despite COVID-19 lockdowns and government travel restrictions, in the last



Long-term patient A from Hertfordshire

financial year we made, as essential workers, 164 visits to patients. Although these were much restricted to dropping equipment on their doorstep and watching them, or their carers retrieve it. We would then contact the patient by phone and talk them through setting up the equipment while parked outside their house. In some circumstances we also collected medication for them from their chemist or surgery.

At all times our deliveries were done using the recommended PPE including face masks, gloves and antiseptic gel. Our team also took



Typical delivery of equipment

precautions of having regular Covid tests and the necessary vaccinations as they became available, making sure they and the wider public stayed safe. Thankfully, through this period none were affected by the virus. Deliveries of equipment further afield was done by third party couriers, overnight stays in hotels were not something we considered as we felt it put those helping us at risk. Nevertheless, despite all restrictions we managed to get the relevant equipment and consumables delivered efficiently and effectively.

We made in excess of 2,000 telephone calls and spent almost the same number of hours on social media to assist and support our patients, a significant increase on last year as we sought new ways of simply keeping in regular communication and dealing with any issues patients encountered as they arose. Our helpline continued to be monitored 24-hours-a-day, with many who called it thanking us for picking up, as they said many helplines offered by other organisations were just answer-phone messages, or obviously left unattended and merely rang and rang. On top of this our regular respiration monitor patients were sent out necessary disposable sensors, and our regular nebuliser patients were sent year packs and necessary disposable accessories. With Covid-19 prevalent, our total of other callers who were concerned about their own breathing conditions, Covid or that of a relative, or friend increased by almost 50% on the previous year. As you may appreciate, this was a 'full on' year of necessary work completed under very difficult circumstances.

Financial

Unlike many of our previous financial years throughout the almost 40-year history of our charity, we entered this year with complete uncertainty, indeed it was quite daunting knowing that Covid, a respiratory virus, could put immense pressure on our small organisation. An unprecedented time, for sure, therefore we put a number of mechanisms in force to ensure we could negotiate our way through the challenging months ahead. We had looked at the opportunities of applying for government and local authority loans to 'see us through' but decided they would be an almost last-ditch option. Instead, we set some up some internal initiatives to survive including capping our spending month on month alongside a temporary Covid savings fund which proved very successful in our ability to cope with fluctuating income, along with our leaning on those bodies offering donations and grants we had built strong relationships with over our many years of existence. Our working with the band of suppliers who again we have forged great alliances with throughout our history, also bore much fruit in tackling the situation, although occasionally interrupted by the staccato of periods of local and national lockdowns. Of course, supply of equipment, much imported from our European neighbours, was affected not only by Covid, but by Brexit. Usual transit lines of goods since the UK's divorce from the EU community has put a somewhat 'spanner in the works' of the free flow of goods in. It's a question of time being a great healer before the raw politics of the situation will quell, which should lead to these lines returning to normal once again.

Our income from this financial year was on a par with that of the previous year, a fine testimony to the loyalty of our many supporters. Whilst we offer thanks to them all, we would like to express a special thank you to the following, The Lynn Foundation, Charlotte Marshall Charitable Trust, NEXT Plc and Persimmon Homes.

During the last weeks of this financial year we were awarded a substantial grant from Nationwide Building Society, which we will expand upon in our next report - 2021-2022. Suffice to say, it ensures a great start to the following year, giving us a firm foundation to work upon. We offer our sincere thanks to all concerned at Nationwide.

Two businesses that have been stalwart donors to us for over 25 years, also come in for a special mention they are, Plato Estates Limited and Marsh Labels Limited.

The pandemic put paid to the fundraising plans we had planned for 2020-2021, it was more of a case of putting events 'on ice', until it was more practical and safer to do so. Having said that, many of our patients and supporters found novel ways of raising awareness of our work and funds for our charity. Many thanks to one such retired lady and her helpers from Bristol, who produced some handmade novelty key rings, which not only championed NARA's cause, but that of the NHS workers too. Promoting these on the internet using various social media sites, including our own their hard work raised £630.25.



During the year, we were also fortunate to have been given a legacy from the estate of the late Emma Hollands, from Hampshire, which amounted to £2,242.45.

Conclusion

As we ended our year, the beginning of the rollout of vaccines was underway, there was a sense of fragile optimism that life was returning to a partial normality with the relaxation of restrictions. However, it was abundantly clear, from all the scientific evidence that a return to the freedoms enjoyed of pre-pandemic world was an almost impossible reality. The best we had on offer was living alongside Covid and the limitations of its gravity for the foreseeable future. Despite the doom and gloom, it was refreshing to look back and realise that, as a charity, we had survived and weathered the storms and obstacles we had been subjected to. Thanks to our prudence and careful financial planning we had proved the robustness and sustainability of our charity,

which had survived one of its' greatest tests. We had delivered a restrictive but positive service to our patients, and in the face of all their frailties and vulnerabilities almost all of them had survived. We know the next few years will offer similar complexities and strains, but we have a firm foundation to move forward positively. As the title of this report mentions, during this tumultuous year, our busy little charity kept calm and carried on.

We leave you with some quotes from some of those we've helped during the year.

Dear NARA,
Thank you again for your on going support!'
Palliative Care
Clinical Nurse Specialist
MacMillan Woodlands Centre
Hinchingbrooke Hospital
Huntingdon

'Thank you so much again for everything you do for our patients, you go above and beyond to help our patients'
Cambridge Respiratory Team

'Thank you so much for your support. We very much appreciate it and I'm sure sure our patients do too!'
Palliative Physiotherapist
Arthur Rank Hospice

'Forever thankful when the hospital let us down NARA came to the rescue and provided us with equipment to put our minds at ease.
The support from Ann and the team is second to none!
What an amazing charity'
Parents of Baby A from Manchester

'Thank you to all at NARA for all your hard work, love and friendship. You've helped us more than you could ever know. It's scary to think how different our life would be without you.'
Parents of A from Northern Ireland

'Thank you so much for sending this out to him, he is very grateful and is feeling better as he is able to breathe better.'
Mr & Mrs P from Middlesex

'This wonderful charity saves lives. They get no official funding and rely on donations. If you can give anything please go to their page and see how they save lives. My friend's little boy is one of the babies they have supported since he was only a couple of weeks old and still keep him alive each night!!'
A friend of 11-year-old J from Liverpool

'Thank you NARA, you again have saved me from a hospital trip. I'm not very well got a tight chest and wheezy, stay safe'
Patient A from Stevenage



Anita Simmons 1953-2021

In early February 2021, the trustees, staff and many of the patients of NARA – The Breathing Charity were saddened at the news of the passing of Anita, especially, Ann Jiggle, and her husband, Mike. It was around the end of 1983, that although living not too far from each other, Anita's and the Jiggle's paths crossed, but by the end of that year, through almost tragic circumstances they got to know each other. The Jiggle's daughter, Kary, who was born in April 1983, suffered from a condition called apnoea, when for no apparent reason she would stop breathing. Despite all medical interventions there wasn't much that could be done other than monitor her every breath 24hrs a day. This was done via a respiration monitor that would alarm should she stop, that cost over £300, which they had to buy themselves.

Just before Christmas of 1983, a knock came at the Jiggle's door where they were met by Anita and her friend. They were collecting for a respiration monitor for her son Iain, who was in hospital after having suffered similar apnoea attacks to Kary Jiggle. Iain was not allowed to leave hospital for his first Christmas without one. Also, sadly, Anita had already lost two other children.

From that point, Anita and the Jiggle family joined forces and helped with fundraising, firstly to purchasing a machine for Iain and later to provide further machines for parents with children suffering similar medical conditions. Eventually, the charity was set up, registered and very soon, thanks to generous giving, had provided around 100 respiration monitors to others suffering from apnoea.

Anita had played a major role in that success, not only by helping to raise funds, but also assisting in delivering equipment and offering advice to worried parents. Although quite private, Anita was a happy-go-lucky kind of person who thought the world of her children and was the life and soul of many fundraising events.

Over the years, we lost touch, until about five years ago when she moved back to the area. By that time, Anita said she wasn't in the best of health and was moving to Wellingborough. Her son, Iain, had become a chef and was in Central America.

Summing up, it's a shame that the charity lost touch with Anita, as she couldn't enjoy the fruits of her initial labours, seeing many smiling faces of the children helped in those embryonic years of the charity.

Today, her legacy lives on through the work and success of NARA – The Breathing Charity, that has given many hundreds of people a quality of life they could not have achieved without its' intervention. A charity which would have never come to fruition had Anita not knocked the Jiggle's door almost 40 years ago. RIP Anita.





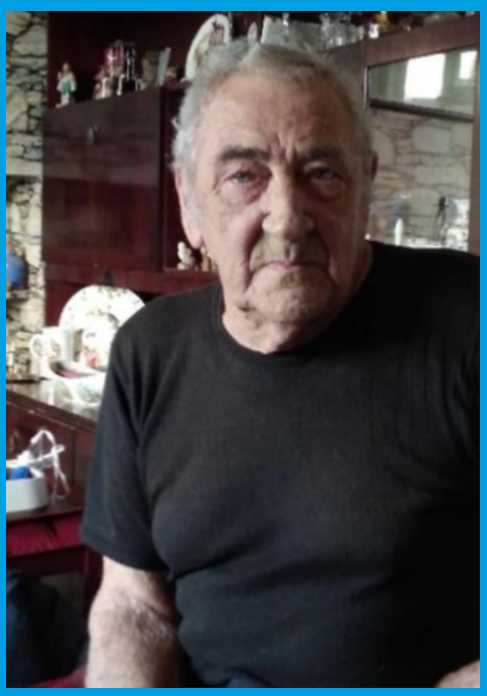
NARA The Breathing Charity
Registered Charity 327033

FINANICIAL YEAR ENDING
30th APRIL 2021

NARA - Annual Charity Accounts

NARA - The Breathing Charity, Moulton Park Business Centre, Redhouse Road, NORTHAMPTON, NN3 6AQ
Phone: 01604 494960 - Fax: 01604 497550 - Website: naratbc.org.uk - Email: info@thebreathingcharity.org.uk
Registered Charity 327033





Caring for all generations

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Charity Information

Trustees	A Jiggle E Atkins K Jiggle
Charity Number	327033
Charity Offices	Moulton Park Business Centre Redhouse Road Moulton Park Northampton NN3 6AQ
Examiner	Andrew Nottingham Taxwright 65 Moss Street Keith Banffshire AB55 5HE
Bankers	Barclays Bank Plc 267 Wellingborough Road Northampton NN1 4YD

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

I report on the accounts of the Trust for the year ended 30 April 2021 which are set out on pages 3 and 6

Respective Responsibilities of Trustees and Examiner

As the charity's trustees you are responsible for the preparation of the accounts: you consider that the audit requirement of Section 43(2) of the Charities Act 1993 (the Act) does not apply. It is my responsibility to state, on the basis of procedures specified in the General Directions given by the Charity Commissioners under Section 43(7)(b) of the Act, whether particular matters have come to my attention.

Basis of Independent Examiner's Report

My examination was carried out in accordance with the General Directions given by the Charity Commissioners. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently I do not express an audit opinion on the view given by the accounts.

Independent Examiner's Statement

In connection with my examination, no matter has come to my attention:

(1) which gives me reasonable cause to believe that in any material respect the requirements
- to keep accounting records in accordance with section 41 of the Act: and
- to prepare accounts which accord with the accounting records and to comply with the accounting requirements of the Act have not been met or

(2) to which in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.



A W Nottingham FCCA
Taxwright
65 Moss Street
Keith
Banffshire
AB55 5HE

Date 10/2/22

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

For the Year Ended 30 April 2021

	Notes	Unrestricted Funds 2021	2020
Incoming Resources			
Donations from Grants, Trusts, Companies and Individuals	2	121,425	120,592
Direct Charitable Expenditure			
Medical equipment care and support		100,691	106,526
Other Expenditure			
Fundraising costs		2,040	3,473
Management and Administration of the Charity	3	10,647	11,978
Total Expenditure		113,378	121,977
Net Movement in Funds for the Year		8,047	(1,385)
Total Funds Brought Forward		34,264	35,649
Total Funds Carried Forward		42,311	34,264

There were no recognised gains or losses for 2021 other than those included in the Statement of Financial Activities.

The notes on pages 5 and 6 form part of these accounts

NATIONAL ASSOCIATION FOR THE RELIEF OF APNOEA

Balance Sheet as at 30 April 2021

	Notes	2021	2020
		£	£
Fixed Assets		33,344	33,344
Current Assets			
Cash at Bank and In Hand		9,453	1,388
Current Liabilities	5	(486)	(468)
Total Assets less Current Liabilities		42,311	34,264
Capital			
Unrestricted Funds		42.311	34,264

Approved by the trustees on 22nd February 22 and signed on their behalf

Trustee

The notes on pages 5 and 6 form part of these accounts

Notes to the Accounts

For the Year Ended 30 April 2021

1 Accounting Policies

1.1 Basis of Preparation of Accounts

The accounts are prepared under the historical cost convention and include the results of the charity's operations which are described in the Trustees' Report and all of which are continuing.

The accounts have been prepared in accordance with the Statement of Recommended Practice for charity accounts.

The charity has taken advantage of the exemption in Financial Reporting Standard No 1 from the requirement to produce a cashflow statement on the grounds that it qualifies as a small charity.

1.2 Income

Voluntary income and donations are accounted for as received by the charity. The income from fundraising ventures is included gross, with the associated costs included in fundraising costs. No permanent endowments have been received in the period.

1.3 Value Added Tax

Value Added Tax is not recoverable by the charity, and as such is included in the relevant costs in the Statement of Financial Activities.

1.4 Fundraising Costs

Fundraising expenditure comprises costs incurred in inducing people and organisations to contribute financially to the charity's work. This includes the cost of advertising for donations and the staging of special fundraising events.

1.5 Management and Administration Expenditure

Expenditure on management and administration of the charity includes all expenditure not directly related to the charitable activity or fundraising ventures. This includes costs of renting and running office premises, staff salaries for administrative staff and fees of an independent examination.

2. Income

	2021	2020
	£	£
Net transfer from savings	2,000	-
Donations	118,635	119,563
Medical Contributions	790	1,029
	121,425	120,592

3. Administration Expenditure

	2021	2020
	£	£
Office Rent and Services	6,081	5,567
Administration Staff	4,080	5,943
Independent Examination	486	468
	10,647	11,978

4. Staff Costs

No remuneration was paid to trustees in the year, nor were any trustees' expenses reimbursed. The staff costs were:

	2021	2020
	£	£
Wages and Salaries	4,080	5,943

The average weekly number of staff employed by the charity during the year was as follows:

	2021	2020
Administrative	1	1

5. Current Liabilities

	2021	2020
	£	£
Accrual	486	468