



ANNUAL REPORT 2021-22

DECEMBER // 2022

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CHAIR OF TRUSTEES

Pathfinders Neuromuscular Alliance has made huge strides this year. A big thank you to dedicated staff, volunteers and supporters for their part in creating such a supportive space, reaching out to others and building on our reputation as a user-led organisation.

There have been a number of projects running and more in the planning stages. The PA Training modules are an example of how the charity listens, identifies a need and does something about it. Congratulations to all involved in bringing this project to life.

With the pandemic still very much present, the online socials have played a vital role in keeping in touch, enabling us to share our experiences and support each other. The Uplift project will also provide opportunities to connect with each other and develop skills. We look forward to seeing how this project develops.

This has been a period of stability, building on foundations and consolidating the charity's position. There is much going on in the background that is not always visible for example, the research project on Transition and the campaigning about Personalised Care needs. Always keeping our core values in mind, the coming year is going to be an exciting one for Pathfinders.



Co-Chair of the Board of Trustees



Sarah Rose - co-Chair of Trustees



Vicky Mozley - co-Chair of Trustees



MISSION

Pathfinders is a user-led organisation by and for people with muscle-weakening conditions. We want everyone to have choice and control over where and how they live their lives, with access to peers, community and connection. We offer social and educational opportunities, providing advice, information, support and advocacy, as well as campaigning, and running projects designed to help our members overcome barriers.

VISION

We want to build a society in which people with muscle-weakening conditions are able to lead full, expansive, and self-determined lives. We believe social care and healthcare should be easily accessible, and treatments should be publicly funded and freely available.

We recognise the skills, aspirations, and achievements of our members, and look to a world which enables everyone to reach their full potential.

VALUES

Pathfinders believes in:

- Being a user-led organisation
- Being diverse and inclusive
- Recognising everyone has different situations, achievements, skills, and aspirations
- Empowering our members
- The value of collective experience
- Working constructively and collaboratively with other organisations
- Campaigning for change
- Creating a positive, fun, and engaging environment

CHARITABLE OBJECTIVES

1. The promotion of social inclusion of people with neuromuscular conditions who are socially excluded from society, or parts of society as a result of having Muscular Dystrophy and related neuromuscular conditions by:

- a) Providing a network of groups that encourage and enables them to participate more effectively with the wider community,
- b) Increasing or co-ordinating opportunities for them to engage with organisations and service providers to enable those providers to adapt services to better meet their needs,
- c) Raising public awareness of the issues affecting them in all areas relating to having a neuromuscular condition,
- d) Providing support to those between the age of 18 and 30 who are socially excluded to establish and grow a business or enterprise to relieve their needs and assist them to integrate into society.

2. To promote and protect the physical and mental health of people with Muscular Dystrophy and related neuromuscular conditions in the United Kingdom as the trustees shall determine.

OUR AIMS



Every year, we look at our aims as a charity, and assess what we have done to achieve those aims. This helps us understand whether we are providing the community with the things we have said we will offer as a charity.

To provide a voice for adults living with Muscular Dystrophy and related neuromuscular conditions

We have engaged on matters of policy, including those around the COVID-19 pandemic, housing, and access to treatments for people with Spinal Muscular Atrophy

To provide information, advice and peer support to adults living with Muscular Dystrophy and related neuromuscular conditions

We have continued to manage peer facilitated support through our online forum

To provide a forum for adults living with Muscular Dystrophy and related neuromuscular conditions to share experiences, ideas and opinions in complete confidence

We have created and updated website resources, and run a range of workshops, talks, and discussion events that have allowed adults with muscular dystrophy and related neuromuscular conditions to network, seek support, and offer support to one another.

To identify, promote, and develop best practice, innovative treatments and technologies for adults living with Muscular Dystrophy and related neuromuscular conditions.



We have identified challenges in the housing market and made recommendations about increasing the stock of accessible housing. We have also supported campaigns for treatments for Spinal Muscular Atrophy to be available to appropriate adults.

We have carried out research into the process of transitioning to adulthood for people with DMD and are currently disseminating those findings and looking to utilise them for policy influence

To campaign and influence treatments for adults living with Muscular Dystrophy and related neuromuscular conditions within health and local authorities, government, relevant professionals, disability organisations and charities.

We have been involved with a range of campaigns, with a particular focus on housing, social care, and personalised care

To work with health and local authorities, government, disability organisations and charities in improving care, support and services for adults living with Muscular Dystrophy and related neuromuscular conditions.

As well as our direct support and advocacy work and our housing research and campaigns, we have led a campaign on allowing people access to their Personal Assistants (PAs) or carers while in hospital, and developed a training package for PAs on supporting people with muscle-weakening conditions

To increase awareness of adults living with Muscular Dystrophy and related neuromuscular conditions.

Through designing training for PAs and carers and our campaign work, we have increased awareness of adults with muscular dystrophy and related conditions

REFLECTIONS



Jamie Hale
CEO

During this financial year, the COVID-19 pandemic has continued to affect our members, and radically limit our ability to undertake in-person work. We have, however, continued to provide a wide range of services online, including support and advocacy, training and development, advice and information, and research and campaigns.

We have been able to develop projects applied for during the previous financial year, ensuring that we have continued to support people with DMD specifically, whilst also widening our provisions for people with other muscle-weakening conditions.

The events and programmes we have run to benefit people with muscle-weakening conditions including direct 1:1 support and advocacy, supporting and managing peer-facilitated discussion and advice spaces, running social events, and leading on a wide range of projects, including research into transition to adulthood for young people with Duchenne Muscular Dystrophy (DMD), designing and running a training programme for Personal Assistants (PAs) of people with muscle-weakening conditions, running an 'online skills' training project for people with DMD, and running an accessible housing campaign.

We also put considerable time into updating our procedures, including a new membership process and fundraising guide.

Finally, we began the process of running UpLift, a National Lottery funded project which will run for four years, supporting young people aged 18-30 to build self-advocacy and campaigning skills through a series of online and in-person events,

A handwritten signature in black ink that reads "Jamie Hale". The script is fluid and cursive.

Jamie Hale

KEY ACHIEVEMENTS

The first independent-living based training programme for PAs and carers designed and led by people with muscle-weakening conditions

[I feel] far more confident in the care I'm receiving

[I have] PAs I trust to understand my needs

The first research project on the experiences of people with DMD, led by people with DMD themselves, giving people the chance to develop their academic skills, and have research published

I wanted to join the project so that I could use my academic research skills to help produce research which may directly benefit others with DMD and other neuromuscular conditions.

I have a personal connection with the research topic, and as a university graduate, I have found using my skills very rewarding.

Projects supporting people with DMD to develop skills as online freelancers, whilst creating resources for the community

I learnt a lot about being part of a team - where everyone has their tasks and the importance of trusting that they will do them.

I felt this improved my confidence and helped me a lot in talking to new people

ACHIEVEMENTS AGAINST OBJECTIVES SET

In our last strategic plan, we prioritised organisational and financial stabilisation and development, increased engagement, information and advice, running campaigns, and events, and securing funding applications for future projects.

We almost completed our policy review, and have the remaining policy development in progress. We also moved to more resilient financial management software, allowing for us to better analyse our financial situation, reflecting our organisational growth.

All our projects are proceeding well and comfortably within reporting deadlines and requirements, and we have added a lot of valuable resources to our website, which we continue to do.

Where we have struggled to reach our objectives, this has been due to limited staff capacity and time - a sector-wide problem, and one we are endeavouring to resolve by trying to create a situation in which staff are not always expected to be working at capacity.

FINANCIAL REVIEW

In our last strategic plan we had the objective of £10,000 of community fundraising during the year. We did not achieve this objective, but identified a number of factors that affected this, and intend to focus on brand, identity, and marketing to support our community fundraising work going forward, alongside applying for funds for this important work.

We set out different objectives for grant fundraising and comfortably achieved those. We are principally funded by grant-making organisations, including the Tudor Trust and National Lottery, by government bodies such as Skills for Care, and by pharmaceutical companies including PTC Therapeutics. We are also funded in partnership working with other neuromuscular organisations such as Duchenne UK.

The funding we have secured from the National Lottery will allow us to run a multi-year project titled UpLift, developing campaign and self-advocacy skills in people with muscle-weakening conditions.

We are confident in the ongoing reserves situation and in the financial stability of the organisation.

OUR WORK

ORGANISATIONAL DEVELOPMENT

We continued to work with Jamie Hale and Jon Hastie as CEOs, and had a significant number of staff across the year including:

- Michaela Hollywood
- Suzanne Glover
- Cath McNicol
- Jacqui Adeniji-Williams
- Adam Langley
- Julian Fiorentini
- Olivia Morgan
- Melissa Gordon
- Sanjeev Mann

We focused on building capacity with regard to social media and membership administration. Our social media work was carried out primarily by Sanjeev Mann whilst funded by the Tudor Trust as a development officer, and included commissioning blogs and articles as well as day to day management and growth. This has benefited our members through the increased awareness and outreach that Pathfinders now has.

By employing Kate Mellor as an administration assistant, we were able to design new membership processes and streamline many of our administration and payroll tasks. This has benefited our members in that less of our charity resource is spent on administration and payroll, meaning members are better contacted and supported, and that staff time is able to be managed to maximise member benefit.

SUPPORT AND ADVOCACY

We have continued our 1:1 support and advocacy work, assisting members, families, and professionals around them. The two key areas of need we have identified have been around access to social care and to employment. This has had a significant impact on the individual beneficiaries. As well as supporting individuals with these processes, we have also ensured that we are providing information for groups who need it.

This includes running a series of sessions around work for people with DMD on the Online Skills project, and the training course we designed for Personal Assistants, with the intention of ensuring better quality support for people with muscle-weakening conditions. This has allowed our work to have a benefit for the wider community of people with muscle-weakening conditions that we serve, regardless of their membership of the organisation.

OUR WORK

PROJECT: UpLift: Disability Advocacy Project



We received a funding agreement for UpLift from the National Lottery - a youth development project focused on supporting people to build skills in areas including self-advocacy and campaigns, whilst also focusing on an independent adulthood with muscle-weakening conditions.

We set up a steering committee and began work on the pilot year, which will run from 2022 to 2023 and includes a range of events on adult living with neuromuscular conditions, including around sex, relationships, driving, care, housing, and independence.

PROJECT: Content Creators Academy

At the start of the year we started our Content Creators Academy; specifically for people living with DMD. This offered training in working freelance as a content creator with DMD, alongside offering paid work in content creation, supporting people in building skills and a portfolio, whilst producing content relevant to other young people with DMD (and other muscle-weakening conditions).

At project outset, we delivered 3 workshops online to support freelance content creators:

1. Becoming a disabled key influencer
2. Permitted work and disability benefits
3. Business planning as a freelancer, and Access to Work funding

We then began to commission work including articles, infographics, and a podcast, which we're looking forward to completing and publishing over the next year.

Duchenne Muscular Dystrophy

5 Ways to a healthy heart

1 Regular heart checks
At least once a year

2 Sleep
6 - 8 hours

3 Water
Drink 2 litres a day

4 Diet
Eat lots of fruit, vegetables and whole-grains

5 Medicine
ACE Inhibitors, Beta-blockers and water tablets can be prescribed.

What are ACE Inhibitors?
Angiotensin-converting enzymes (ACE) inhibitors help blood vessels to relax and open. This can reduce your blood pressure. This means that your heart doesn't have to work as hard.

Beta blockers slow your heart down. They're often used alongside ACE inhibitors.

Other medications?
Lots of other medications can be deployed when needed, depending on how advanced your heart condition is. Some of these include anti-fibrosis medications, SGLT2 inhibitors and water tablets.

What is an Electrocardiogram?
An electrocardiogram, or ECG, monitors your heart's electrical activity through several electrodes (little stickers) placed on your body. It's a quick and painless procedure.

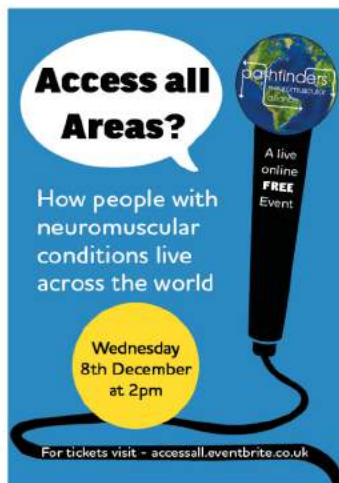
What is an Echocardiogram?
An echocardiogram is a type of ultrasound scan, it shows your heart on a monitor so the cardiologist can examine it. It's painless and non-invasive.

This is not a substitute for professional medical advice. Please speak to your doctor before making any lifestyle or medical changes.

OUR WORK

PROJECT:

Online Skills Training



We designed a project for people with DMD, connecting young people with DMD, adults with DMD, and parents of young people with DMD, focused on Encouraging Independence, through online webinars and coaching sessions titled Ask the Adults, Ask the Parents, and Ask Gen Z, leading to open conversation and connection.

We also worked with two cohorts of young people with DMD to support them in developing skills to run online events, through weekly event planning meetings and workshops led by people with muscle-weakening conditions. These covered research, marketing, flyer design, and public speaking. The workshops empowered young people with DMD to run online events, including Shut Up and Drive - an event on driving with DMD, Wheelie Good Holidays - an event on travelling with DMD, Anime Explained, and Access All Areas.



The project had a significant impact on a wide range of participants. One mother noted that her son had gained some confidence and "it was a good opportunity for him to engage with others online and do something different". Another participant said "I felt this improved my confidence and helped me a lot in talking to new people" and others said they had become more confident in "presenting in front of people", "working as part of a team", and "being able to speak clearly".

RESEARCH: Transition to Adulthood with DMD

We have continued into a second year of our peer-led research into transition to adulthood for people with DMD. This research has developed significantly with important findings emerging. Our Research Officer, Dr Suzanne Glover worked with peer researchers to carry out interviews across Europe, analysing them to understand how adults with DMD understand their experiences of transitioning to adulthood.

It showed how young adults with DMD often see the world as incompatible for people with DMD when considering many of the important milestones of transition to adulthood. This includes transitions in educational settings, post-educational opportunities, as well as navigating new and existing social relationships entering adult life. The research suggests that much of this perceived incompatibility is fuelled by experiences of ableism and subsequent internalised ableism. Once the analysis has been completed, we will be focusing on disseminating these findings, hoping to use them to create change.

OUR WORK

RESEARCH: Housing Accessibility Campaign

This took place from April to October, and was a research study and scoping exercise to inform future work on housing accessibility for adults with DMD.

Dr Jon Rey-Hastie (CEO at Pathfinders) worked with Dr Janet Hoskin at the University of East London to carry out research into future housing accessibility for adults with DMD. This found that there is not enough accessible housing in the UK and not enough information available for people to find current accessible housing.

This led us to make key recommendations, including:

- Information about finding accessible housing on the private housing market needs to be readily available and accessible for disabled people
- Information about finding social housing needs to be readily available and accessible for disabled people
- Government and Local Authorities must commit to increase the provision of accessible housing
- Local Authority housing services should be joined up with social care and health support

This research has led to a better understanding of the housing market for disabled people, with benefit to disabled people more broadly, outside our membership, but grounded in a specific knowledge of the needs of people with neuromuscular conditions. The knowledge has also informed much of our support and advocacy work around housing.

"Working on the accessibility housing research project illuminated to me the amount of work there is yet to be done to get enough suitable accessible housing in the UK.

On a personal level, working on this project was my first employment and gave me confidence and I built on skills I had gained at university. The project also led to my following two employed positions at Pathfinders"

Kate Mellor

OUR WORK

PROJECT: Training for PAs and Carers

Pathfinders identified that people with muscle-weakening conditions often have specific requirements in accessing personal support, and that having a training programme for Personal Assistants (carers) of people with muscle-weakening conditions would be very beneficial. Through informal polling and discussions with members, we identified significant challenges with recruitment and retention, and a lack of training material which both explored the common factors shared by people with muscle-weakening conditions, and the role of the PA.

This training programme offers a transferable certification of completion, allowing PAs to move between roles while demonstrating knowledge of the needs of our community.

We developed 13 modules in total:

1. Introduction to neuromuscular conditions
2. Independence and the social model of disability
3. Neuromuscular conditions and common emergencies
4. Common equipment used by people with neuromuscular conditions
5. Ventilation
6. Posture, skin and position
7. Swallowing and nutrition
8. Physiotherapy and exercise
9. Working in someone's home and workplace
10. Supporting disabled people as parents
11. Respect, intimacy and personal care
12. Supporting people with sex and relationships
13. Supporting people with their emotional health

I feel that the course has given me some reassurance in my management of carers. It's encouraged me to remember I always have choice in my care and I must always speak up about my preferences.

I've been employing carers for over 10 years and I've never come across training that is so relevant and up-to-date for someone with a muscle wasting condition. I frequently send carers on mandatory training which does not cater for any of my specific care needs. I feel this can have a negative impact on the quality of my care and staff morale. I can honestly say that there has been a buzz in the air with my care team over the past few weeks because of this training.

The modules were all led by people with muscle-weakening conditions, with specialists contributing where appropriate, and were delivered across a range of training days.

Following the end of this project, these modules are available for free online for anyone to take - whether a PA or carer, a friend, a family member, or a professional, offering a range of information in what muscle-weakening conditions are and how they affect people.

Prepared by Jamie Hale for the Board of Trustees, November 2022

With thanks to:

The staff, trustees and volunteers who keep Pathfinders going, and the members who generously share their advice and support in our facebook groups and at our events.

Thank you for your continued support of Pathfinders

Contact:

General - info@pathfindersalliance.org.uk

Trustees - trustees@pathfindersalliance.org.uk

CEO - Jamie Hale jamie@pathfindersalliance.org.uk

Charity Name		No (if any)		CC16a
Pathfinders Neuromuscular Alliance		1155884		
Receipts and payments accounts				
For the period from	Period start	To	Period end	
	6th April 2021		5th April 2022	

Section A Receipts and payments

	Unrestricted to the nearest £	Restricted to the nearest £	Endowment to the nearest £	Total to the nearest £	Last year to the nearest £
A1 Receipts					
Fundraising	5,463	-	-	5,463	4,149
Grants	37,565	195,837	-	233,401	78,789
Reimbursements	5,199	-	-	5,199	3,651
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross)	48,226	195,837	-	244,062	86,589
A2 Asset and					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	48,226	195,837	-	244,062	86,589
A3 Payments					
Bank interest and charges	102	12	-	114	69
Employment costs	29,396	79,995	-	109,391	49,419
Insurance, governance, and	4,078	2,045	-	6,123	2,693
Office, equipment and	7,799	-	-	7,799	3,500
Project and event costs	53	11,682	-	11,735	354
Promotional activity		210	-	210	168
Payment and transaction costs	2	-	-	2	1,030
	-	-	-	-	-
	-	-	-	-	-
Sub total	41,430	93,944	-	135,374	57,233
	CORRECT	CORRECT			
A4 Asset and					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	41,430	93,944	-	135,374	57,233
Net of receipts/(payments)	6,795	101,893	-	108,688	29,356
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	37,952	32,478	-	70,430	41,073
Cash funds this year end	44,747	134,371	-	179,118	70,429

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted to nearest £	Restricted to nearest £	Endowment to nearest £
B1 Cash funds		44,747	134,371	-
		-	-	-
		-	-	-
	Total cash funds	44,747	134,371	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets	Details			
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities	Details	Fund to which	Amount due	When due
	Unpaid invoice to NJC Secretarial	PTC Research	58	13/10/22
	Unpaid invoice to Luca Buccella	PTC Research	1,156	30/11/22
			-	
			-	
Signed by one or two	Signature	Print Name	Date of	
	 Sarah Rose (Dec 12, 2022 18:37 GMT)	Sarah Rose	Dec 12, 2022	
	 Victoria Mozley (Dec 13, 2022 13:41 GMT)	Victoria Mozley	Dec 13, 2022	

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF PATHFINDERS NEUROMUSCULAR ALLIANCE

I report to the trustees on my examination of the accounts of Pathfinders Neuromuscular Alliance ('the charity') for the year ended 5 April 2022.

Responsibilities and basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities and Trustee Investment (Scotland) Act 2005 (the '2005 Act'), the Charities Accounts (Scotland) Regulations 2006 (as amended), and the Charities Act 2011 ('the 2011 Act'). You are satisfied that your charity is not required by charity law to be audited and have chosen instead to have an independent examination.

I report in respect of my examination of the Trust's accounts carried out under section 44 (1) (c) of the 2005 Act and section 145 of the 2011 Act. In carrying out my examination I have followed the requirements of Regulation 11 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and all applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 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 giving me cause to believe that in any material respect:

1. accounting records were not kept as required by Section 44 (1) (a) of the 2005 Act and Regulation 4 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and section 130 of the 2011 Act; or
2. the accounts do not accord with those records; and
3. the accounts do not comply with the accounting requirements of Regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

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.



Mr J P Foxwell FCCA FCIE
independent-examiner.net

39 Enfield Road, Poole, BH15 3LJ

Date: 13 December 2022

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		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
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			-	-
			-	-
			-	-
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			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
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Responsibilities and basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities and Trustee Investment (Scotland) Act 2005 (the '2005 Act'), the Charities Accounts (Scotland) Regulations 2006 (as amended), and the Charities Act 2011 ('the 2011 Act'). You are satisfied that your charity is not required by charity law to be audited and have chosen instead to have an independent examination.

I report in respect of my examination of the Trust's accounts carried out under section 44 (1) (c) of the 2005 Act and section 145 of the 2011 Act. In carrying out my examination I have followed the requirements of Regulation 11 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and all applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 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 giving me cause to believe that in any material respect:

1. accounting records were not kept as required by Section 44 (1) (a) of the 2005 Act and Regulation 4 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and section 130 of the 2011 Act; or
2. the accounts do not accord with those records; and
3. the accounts do not comply with the accounting requirements of Regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

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.



Mr J P Foxwell FCCA FCIE
independent-examiner.net

39 Enfield Road, Poole, BH15 3LJ

Date: 13 December 2022