



**Annual Report
1st April 2022 to 31 March 2023**



**PIP-UK
Poland Syndrome Support &
Network**



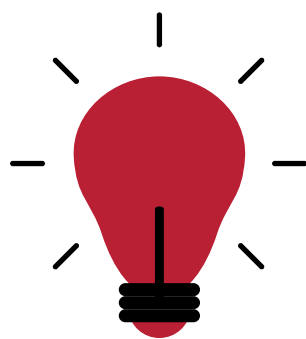
**www.pip-uk.org Charity Registration Number
:1188941**





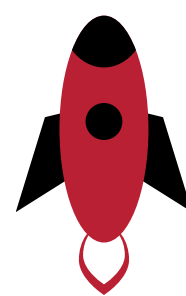
Vision

We will be the centre of expertise for Poland Syndrome Research, Wellbeing & Support Services and Connection.



Mission

Advocate for earlier, consistent diagnosis and treatment paths for the Poland Syndrome community. Building awareness for Poland Syndrome and providing support to the community.



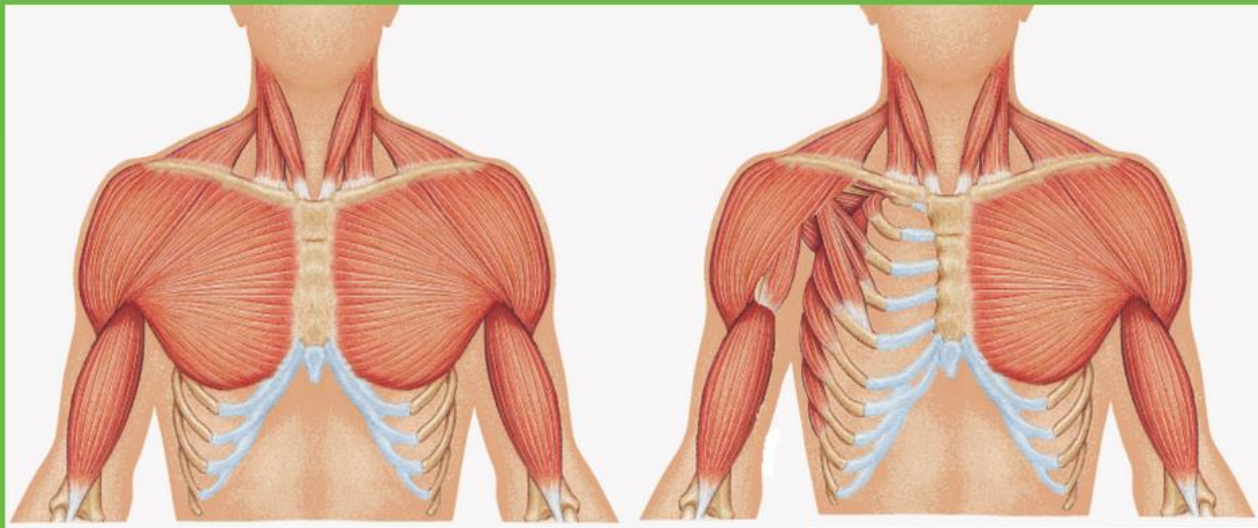
Goals

Our main goals are centred around generating scientific activity, supporting the wellbeing of & connecting people across the Poland Syndrome Community.

Poland Syndrome

About Poland Syndrome

Babies are born with underdeveloped chest muscle on one side.



Typical symmetry seen in pectoralis major muscles

Asymmetry seen due to absent pectoral muscle

Poland Syndrome is a rare birth difference named after Dr Alfred Poland credited with its discovery

Chest Differences

01

80-99% OF PEOPLE WITH POLAND SYNDROME HAVE: ABSENT OR UNDERDEVELOPED:

- CHEST MUSCLE
- BREAST
- NIPPLE

02

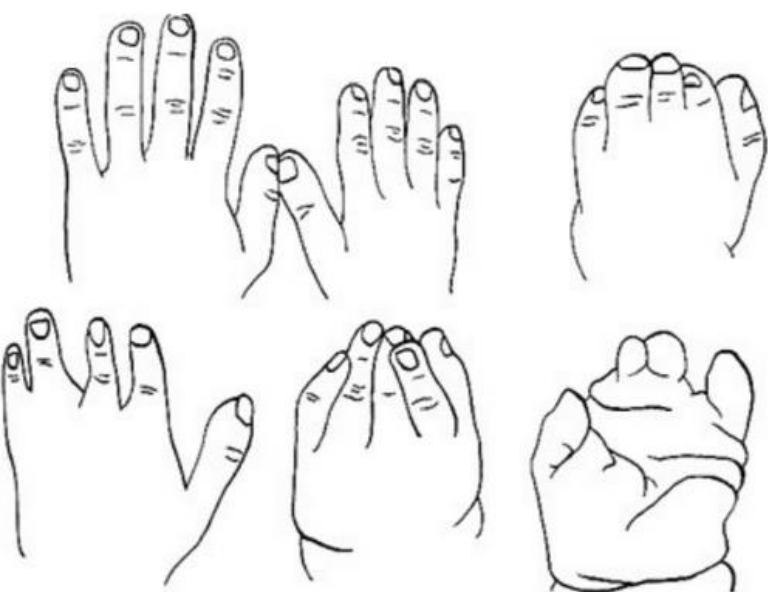
5-29% of people with Poland Syndrome have: Aplasia/Hypoplasia of the sternum



“

Hand Differences

POLAND SYNDROME CAN AFFECT ONE HAND ON THE SAME SIDE OF THE BODY. VISUALLY SMALLER OR FUSED FINGERS, ABSENT OR SHORTENED



01

5-29% of people have Finger syndactyly

02

30-79% of people have Finger symphalangism or Fused Finger bones



About PIP-UK

We set up PIP-UK in 2011, initially as a community group, to raise awareness of Poland Syndrome (PS) and to improve the lives of people living with PS. First we created a website to raise awareness, set up a phone line, then a Facebook page for sharing experiences, and connecting with others. Like us, some of the families we connected with were struggling to get the right diagnosis for their children. We soon realised that many people had lived much of their lives without a proper diagnosis of PS, even connecting to people in their 80's without a diagnosis. This left many people with not just the physical difference to contend with but mental health issues from a life lived without a diagnosis, thinking they are the only person in the world that was born like them.



PIP-UK has created a community group, peer support events, wellbeing sessions, family fun days, children's clinics and a global Poland Syndrome register to better understand the condition and how it manifests in those with it. All activities are free to access with an optional donation to the community and it is for all ages.



Our year in numbers

Our year in numbers:

15 people were supported with one-to-one advocacy and helped with direct appeals to the NHS for treatment;

6 Poland Syndrome Clinics held and supported at Birmingham Childrens Hospital with 30 children and their families in attendance;

244 - that's the number our membership grew to this year;

244 - that's the number our register participants grew to this year;

272 plus phone calls and emails answered for one-to-one support;

40000 people reached on social media;

1 finalist place in the Smiley Charity Film awards

1 partnership with RareQoL;

30,000 pounds in grant money received for our support services and events;

13,000 pounds raised by the community to support our work.





Our Major Achievements

We have had a tremendous year of growth and support and our small charity and community has grown by leaps and bounds.

- Living Well programme supported the wellbeing of adults and ladies with Poland Syndrome
- We supported more people than even before with 1-2-1 Support and Advice
- Our volunteer team increased significantly and our board grew.
- Our childrens clinic benefitted more families than ever before
- Our Poland Syndrome Community Register participants grew significantly and we published case studies, posters and journal articles to raise awareness
- We hosted more events for the community than ever before in a variety of locations with different activities to meet all community needs





Family Day 2022

Research has shown that empowering patient associations- such as PIP-UK- can help to improve the lives of those living with rare diseases (Baldelli et al., 2019), and therefore I would like to extend a special thanks to the Mayor of Stockport, Counsellor Adrian Nottingham, who showed his support for PIP-UK's Awareness Fun Day by visiting the event and handing a thank you certificate to each of the dedicated volunteers who assisted PIP UK in making the day possible. I would also like to extend gratitude to Natalie Barron, of Love Hair Salon, for her kind donation of £500 who- having a child born with Poland Syndrome- wanted to show support for this family centred event. Her donation meant that PIP UK were able to hire such a wide range of activities like the gaming truck, going a long way to making the event a success. Hopefully PIP-UK can continue its great work and organise more inclusive community events in the future!

Written by Tiegan MacAulay.

Tiegan is an Undergraduate Forensic Psychology student at the University of Chester. Tiegan recently spent a week volunteering for PIP-UK as part of student placement initiative with the University and Dr Sondra Butterworth from RareQoL. RareQoL is a social enterprise on a mission to improve the lives of the rare community and PIP-UK is a member of the RareQoL network. Huge thanks to Tiegan for all the fantastic work and Dr Sondra Butterworth for making this placement accessible to our small charity.





Family Day 2022

PIP-UK celebrates Poland Syndrome Awareness Day with Fun Day Meet-up!

For Poland Syndrome Awareness Day on April 30th 2022, PIP-UK organised an ‘Awareness fun day’ social event to support individuals who have been impacted by Poland Syndrome and to raise public awareness about the condition and the difficulties that those born with Poland Syndrome may experience.

The Awareness Fun Day was held at Rose Walker Centre in Stockport, owing to the Cheadle Heath Community Association’s generous donation of venue hiring to PIP-UK, and was well-received by both the general public and those born with Poland Syndrome. It featured a range of outside activities for children and adults to participate in, such as ball games and skittles, thanks to the event’s great location, situated near a lovely outdoor park. Inside the centre, attendees were able to showcase their artistic ability and bond through creativity with the help of Malcolm and Amang from Claytime, a local community group. PIP-UK also sought out a gaming truck to ensure that all children, regardless of their interests, had something fun to engage with! By providing a variety of activities, this awareness fun day allowed children who are affected by Poland Syndrome to be around a community of peers who understand what they are going through, reducing some of the isolation or bullying that those with the condition may experience as a result of being perceived as “different” from those without the condition (Adama et al., 2021).



Families were also able to speak with one another about their experiences with Poland Syndrome at the event, a beneficial resource when raising and caring for individuals with rare diseases (Baumbusch et al., 2018). Charlie’s mother, Jade Robinson, learned about the event after seeing it promoted on a banner. She was able to get assistance from other families dealing with Poland Syndrome as a result of her attendance, being welcomed into the community by trustees and other attendees. Charlie also loved the event as he was able to connect with other children who shared the same condition with him in a fun and activity filled environment. Events like these are fantastic because they give a safe area for people with rare diseases- such as Poland Syndrome- to share and interact with others who are in the same boat as them. Jade would not have known about PIP-UK and the community they could provide her and her son if it hadn’t been for this Awareness Fun Day.



Living Well Programme Report and Impact

PIP UK created two new Living well session this year. Living Well for Adults with Poland Syndrome and Circle of support for Ladies with Poland Syndrome.



Circle of Support

🌻 Creating a Safe Haven: Poland Syndrome Support Sessions for Women 🌈 🌸

Over 6 week ladies from our community were invited to go on a Journey of Support and Connection. It was a unique opportunity to embark on a journey of support, understanding, and community. Led by the compassionate guidance of Susanna Guest, these sessions were designed to provide a gentle space for self-discovery and connection.

Key Objectives and Outcomes:

Welcoming You As You Are:

The sessions offered a warm embrace, inviting you to bring your authentic self. No matter where they are on their Poland Syndrome on your journey it offered a safe haven for expression and permission to participate just as you are.



Living Well Sessions Circle of Support Report and Impact



The platform is created for the ladies to be heard, seen, and acknowledged. Through carefully crafted activities based on feedback from the community in previous events, the ladies voices and experiences found resonance in the group.

Building a Community of Shared Experiences:

The group got to connect with a community of women who share the common bond of being born with Poland Syndrome, which is only possible because of PIP-UK. The group experienced the power of shared narratives, fostering a sense of belonging and understanding. The sessions instilled a profound sense of togetherness among participants.

Outcomes

Those who participated in the programme took both an opening and closing survey which allowed improvements to be tracked over the course of the six weeks.

100% of participants would recommend these sessions to others with Poland Syndrome.

Participants reported:

“A place of people with the same condition is priceless, nobody can understand what you feel except of those who are the same as you”



Living Well Sessions Circle of Support Report and Impact



“I've learnt to find a little time just for myself, to relax, to feel just present”

“I feel I can now disassociate myself from things in moments of stress and take a moment to breathe, relax and think things through. I am much more conscious of making sure I am taking care of myself and not allowing my overthinking tendencies to worsen things. I try and take moments to reflect more, which is something I hardly ever did before. I also try not to beat myself up over things I can't control, and also acknowledge the fact we are all on different paths in life and just because I've had hurdles and am not at the same point in life as some of my other peers doesn't mean I'm a failure. I've come to terms with the fact that actually I've had to deal with a lot more than some of them have, and I'm doing pretty well to be where i am now having overcome them. I am focusing a lot less on materialistic things like savings, having a job etc and much more on reassuring myself that I'm in the right direction and still doing well. Before the course I was so wrapped up and worried about how my Poland Syndrome surgeries had set me back, but now it's the opposite- I just view it as something I've overcome.”

“"Without the guidance of Susanna and the circle of support, I'd still be lost, she helped me find my way back. It's liberating! I'm feeling a lot calmer, relaxed and in control, and a lot more confident, I've been able open up and raise awareness of Poland Syndrome to a family member recently, where previously I wouldn't have been able to so. I have gained much more confidence. These sessions are life changing, not in a drastic way, but in a very subtle way.“

“I highly recommend these sessions to other women with Poland Syndrome, as it's gently guided by an expert.”



Living Well Sessions Circle of Support Report and Impact



“Without the guidance of Susanna and the circle of support, I'd still be lost, she helped me find my way back. It's liberating! I'm feeling a lot calmer, relaxed and in control, and a lot more confident, I've been able open up and raise awareness of Poland Syndrome to a family member recently, where previously I wouldn't have been able to so. I have gained much more confidence. These sessions are life changing, not in a drastic way, but in a very subtle way.”

“I've heard other's people stories and there's nothing more that inspires me more”

“These sessions are gently guided, you feel welcomed, come as you are, no pressure on you at all, you feel neutered, safe and accepted, you are heard, and you will be with other women who have Poland Syndrome.”

“Please consider funding these sessions again next year, as they make a huge difference in the wellbeing of us people living with Poland Syndrome, they're essential year on year!! Thank you”

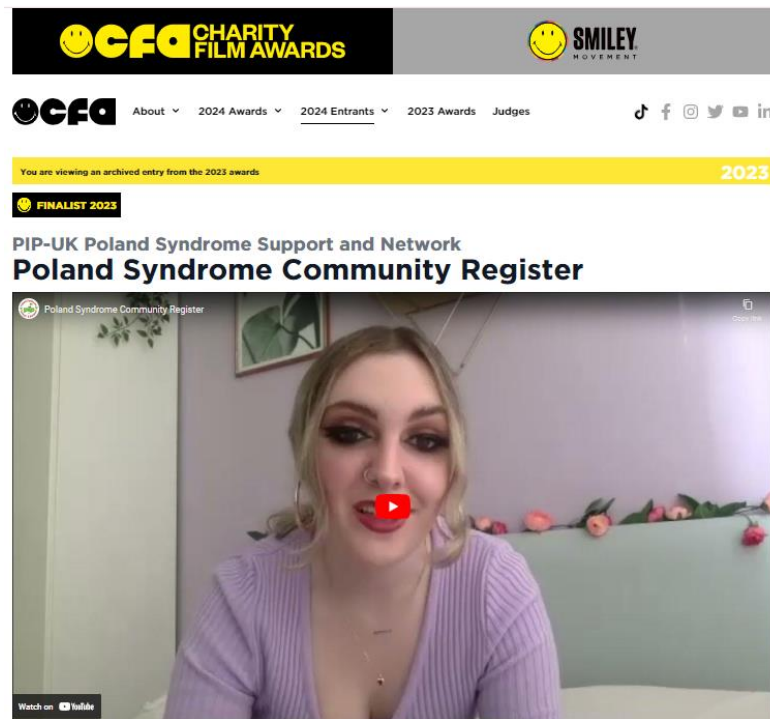
“I was able to open up and raise awareness of Poland Syndrome through a Direct Message to a celebrity, which would have virtually been impossible for me to do before the sessions.”

Our heartfelt gratitude extends to The National Lottery Community and Lottery players for their support in making these sessions possible. We eagerly anticipate the positive impact these sessions will have on the lives of women navigating the Poland Syndrome journey. PIP UK would like to continue working in the future to promote the mental health of persons born with Poland Syndrome, based on the success of this programme.

We are planning annual sessions for 2022 and 2023 for all ages.



Film Award Finalists



Our amazing ambassador Becca Butcher created a video to launch our Poland Syndrome Community Register in 2021. This film featured community members from all around the world documenting their journey with Poland Syndrome, the challenges they have faced and what the community register means to them and the future of Poland Syndrome.

The film was so powerful it was nominated for an award at the Smiley Charity Film awards. Dubbed ‘The Oscars of the charity world’, it was a real honour. More importantly the film marked this first time anyone captured the real story of living with Poland Syndrome, its an emotional watch and really resonated with our community and galvanized the phenomenal support for the register.

We didn’t take away the award on the night, but we did get to celebrate the occasion with our ambassador Richard Stott who features in the film and young Trustee Kira Aspland. Amazingly the awards have generated 300 million film impressions and attracted over 500,000 people to tune into the 2023 virtual event. Ensuring our video reached more people to raise awareness of Poland Syndrome than ever before. We established a relationship with the Smiley News charity who lead the awards and are working on future video projects too.

You can hear from Nan, Becca, Kim, Richard, Lewis, Gift, Gene, Stuart, Manuel, Lily, Sydney, Rupinder, Trudie and Ericka, as they share their experiences of living with Poland Syndrome and why they think the Poland Syndrome Community Register is important by viewing here: <https://pip-uk.org/poland-syndrome-community-register> & <https://smileycharityfilmawards.com/films/poland-syndrome-community-register>



Living Well Sessions Report and Impact



🌟 Living Well with Poland Syndrome Sessions: A Transformative Impact Report!** 🌈 🤝

****Embarking on a Journey of Wellbeing:****

In 2022 we opened our virtual doors to those adults seeking support and empowerment on their Poland Syndrome journey. In a continuation of our "Living Well with Poland Syndrome" sessions. These sessions, designed to foster connection, build confidence, and reframe negative experiences, have a truly transformative impact.

Trainee Psychotherapist and Chair of the board, Angel Scott-Bottoms, guided participants through this 6-week journey. With a wealth of experience and a compassionate approach, Angel created a supportive space for individuals to come together, share, and grow.

The group participated in activities and discussions geared towards boosting self-confidence and fostering a positive self-image. Helping people to embrace the unique strengths that define your journey with Poland Syndrome. The group were able to forge meaningful connections with individuals who share similar experiences. The power of a supportive community lies in the understanding and empathy it provides. Together, they navigated the challenges and celebrated the triumphs.

The group explored techniques and strategies to reframe negative experiences, turning challenges into opportunities for growth.



Living Well Sessions Report and Impact



By shifting perspectives, participants were assisted to cultivate resilience and embrace a more positive outlook. These sessions served as a platform for personal growth, resilience, and the cultivation of a sense of community. By actively engaging in discussions and activities, participants embarked on a journey towards living well with Poland Syndrome.

Outcomes

Those who participated in the programme took both an opening and closing survey which allowed improvements to be tracked over the course of the six weeks.

100% of participants would recommend these sessions to others with Poland Syndrome.

When asked to share something you have done as a direct result of the course that you may not have done before, our participants said:

“Speak to my parents more about their experience with having a child who has Poland Syndrome, and learning more about their thoughts and their processes in that journey.”

“It's helped me connect to people with whom I never would have been able to connect with, and to learn more about other people's experiences with Poland Syndrome. “



Living Well Sessions Report and Impact



When asked to share what you would say to others who are thinking about taking part in future sessions to help them decide, they said:

“Don’t be afraid. Do it”

“It can really help you gain perspective, learn about others and from others, and also learn to love yourself more and be more confident and open to sharing your story with Poland Syndrome.”

Our heartfelt gratitude extends to The National Lottery Community, Mazars Trust, Lowestoft Council and Lottery players for their support in making these sessions possible.

PIP-UK would like to continue working in the future to promote the mental health of persons born with Poland Syndrome, based on the success of this programme and the need within the community.

We are planning annual sessions for 2023 for younger children.



Poland Syndrome community register 2023

Real-world data from registries and other real-world evidence sources remain a fertile ground of opportunity for advocacy groups and biopharma companies to accelerate rare disease research and better characterize and manage these diseases, their progression and treatment.

OBJECTIVES

To answer this challenge, PIP-UK was focused on ensuring that the data were collected in a standardized way, met regulatory requirements and aligned with their vision to build global collaboration, with the technology as a nucleus for patients to convene and share their experiences.

METHODS

PIP-UK started working with Pulse Inf FRAME in 2021 to launch the Poland Syndrome Community Register. Utilising the Pulse Platform, PIP-UK were able to deploy the registry within 4 months with a recruitment target of 100 participants in the first 3 months. Common data elements to form the central hub for data to be characterized and curated were created. PIP-UK and Pulse addressed the regulatory requirements that would be needed for drug development by ensuring that the data are collected in a platform that adheres to FDA and EMA data standards and further provides confidence to participants that their data are stored safely due to compliance with HIPAA and GDPR.

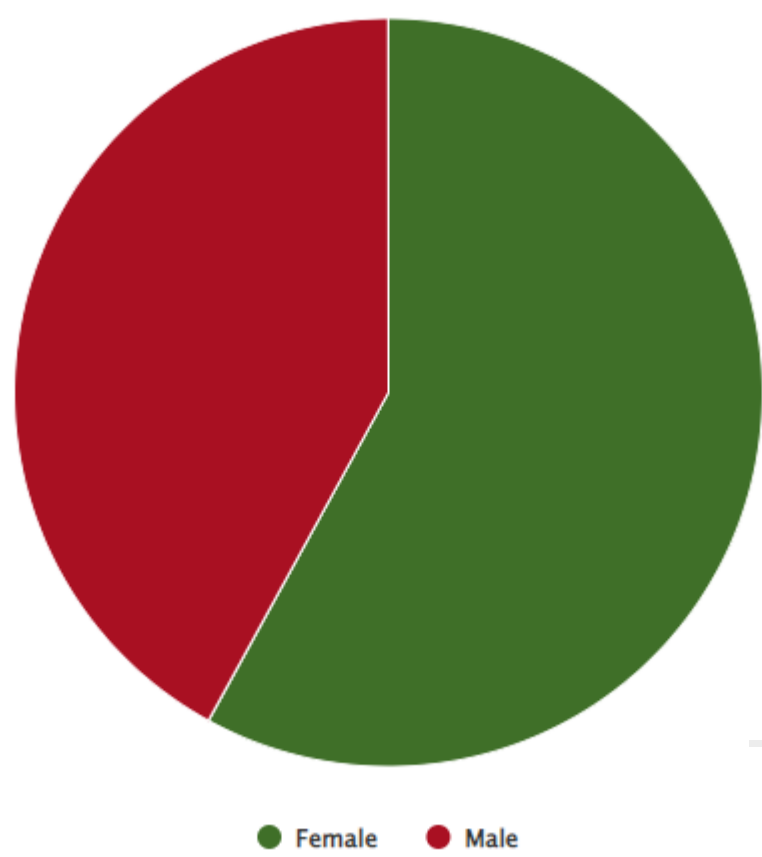
RESULTS SO FAR

The registry currently has 219 active participants enrolled into the platform where 31 of them are under the age of 10. The majority of participants are female and right side affected. The majority of participants are diagnosed between ages 0-9 years but a significant number aged 10 and over with the latest reported diagnosis aged 60+.



Poland Syndrome community register 2023

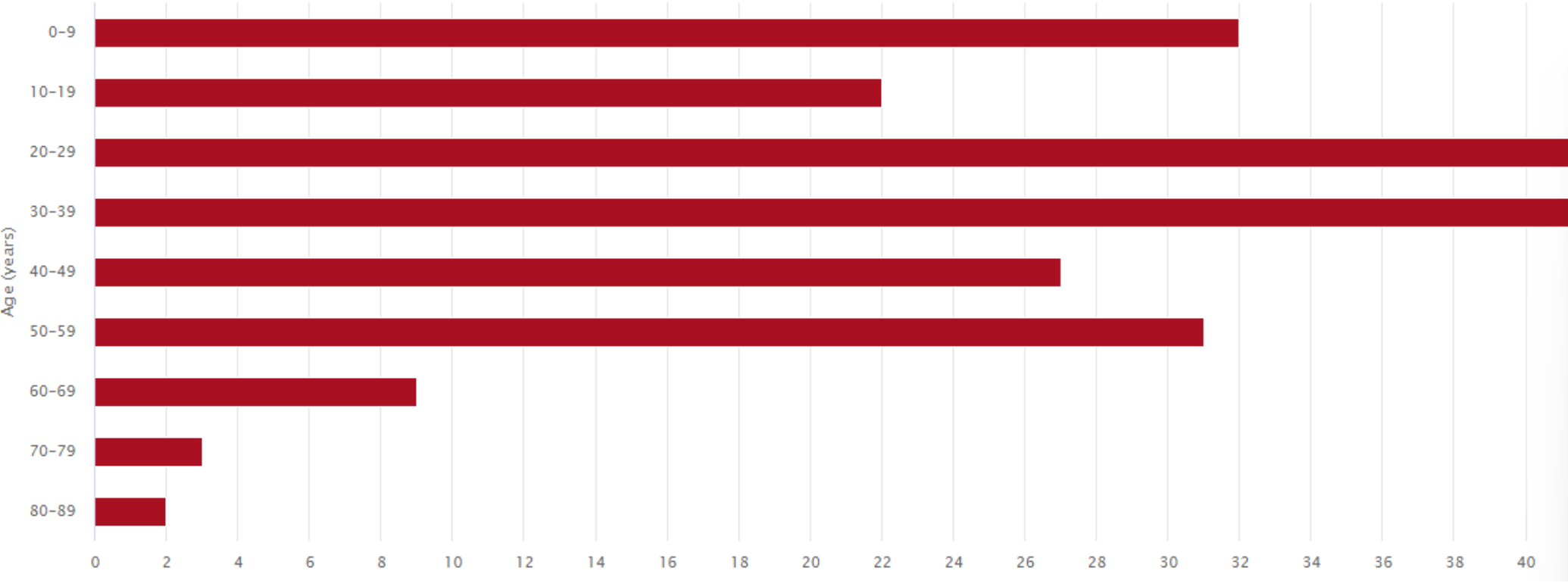
Sex of Participants



Participant Ethnicity



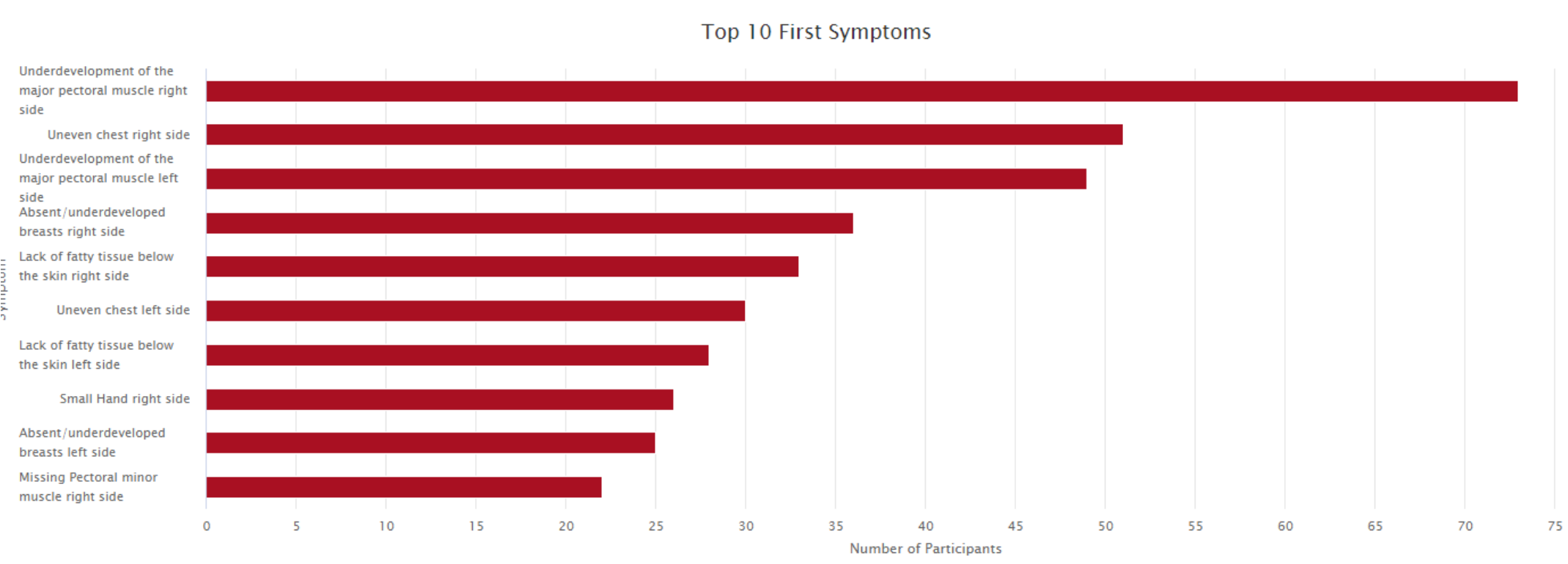
Age of Participants



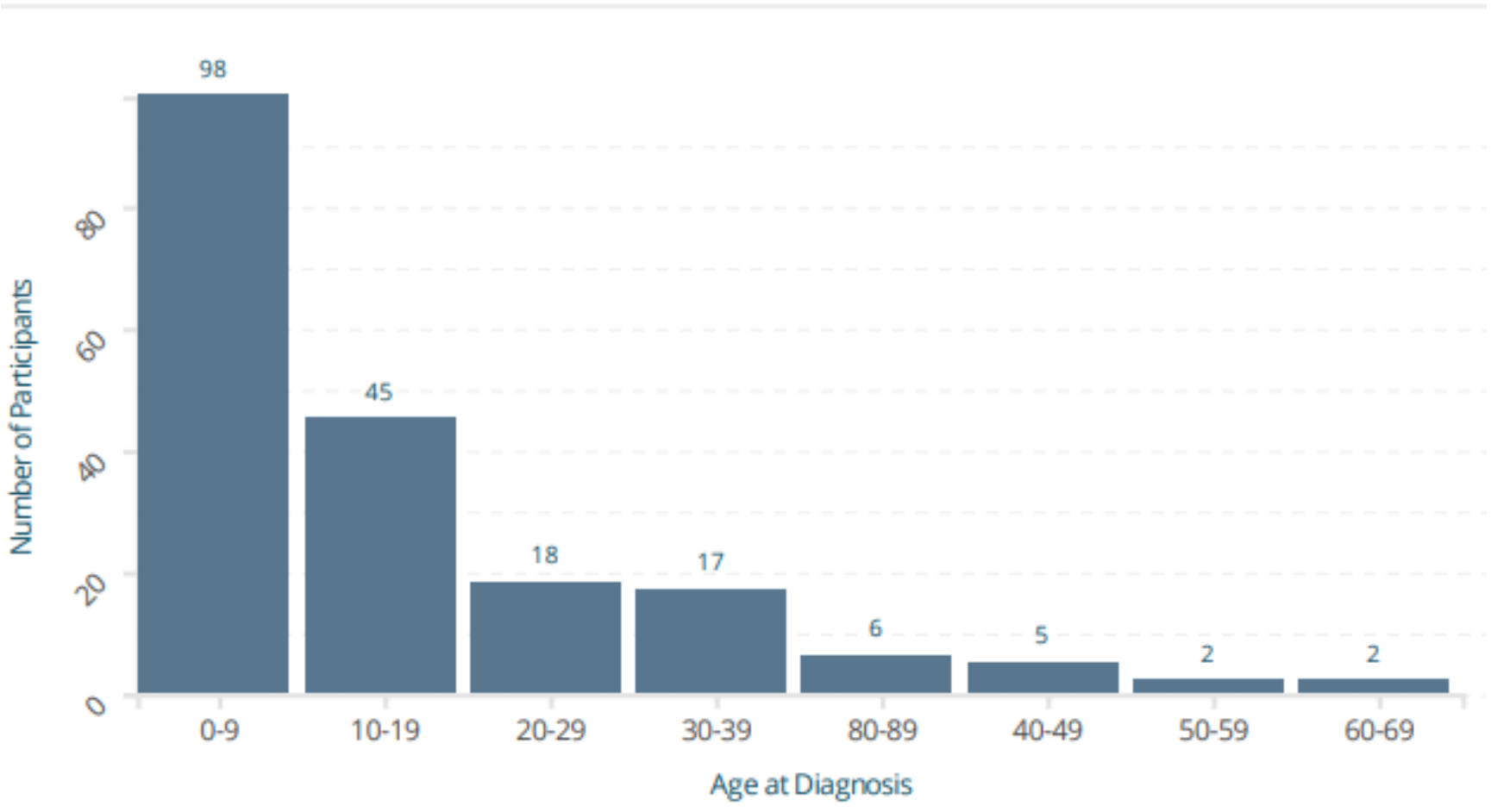


Poland Syndrome community register

2023



Age at Diagnosis



CONCLUSIONS

Our community is engaging regularly with the register and updating their quality-of-life survey every 6 months. We are just getting our scientific advisory board off the ground to complete the first major analysis of the data. We have doubled the number of participants in the first year and look set to do the same for the second year. We will need major investment in research and advancements of the register to tackle the research the community needs. We continue to work on funding applications to support this but have yet to be successful.



Poland Syndrome community register 2022 – Case Study

In July 2022 Pulse Infoframe Inc. produced a case study about how our community came together to get the Poland Syndrome Registry started.

It talks about how the community united and engaged so well with the register to open the door to research into Poland Syndrome. The register is still growing and we are working on building relationships with researchers.

Read the full case study here: <https://www.pulseinfoframe.com/case-study-how-to-properly-recruit-participants-for-a-registry/>

Case Study: How to Properly Recruit Participants for a Registry

JULY 21, 2022 | RYAN SHEEDY | BLOG, CASE STUDIES, NEWS

Shattering Rare Disease Registry Recruitment Targets with PIP-UK

Real-world data from registries and other real-world evidence sources remain a fertile ground of opportunity for advocacy groups and biopharma companies to accelerate rare disease research and better characterize and manage these diseases, their progression and treatment.

Historically, the barriers to maximizing the value of registry data include:





Poland Syndrome community register 2023 – 1st Journal Article Publication

In March 2023 our CEO Sam was a co-author in a Journal article about creating patient registries.

Sam worked alongside leading professionals in the Rare Disease world Paul Wicks, Lindsey Wahlstrom-Edwards, Andrea Downing & Elin Haf Davies

Read the full article here :

<https://link.springer.com/article/10.1007/s40271-023-00619-w>

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So You Want to Build Your Disease's First Online Patient Registry: An Educational Guide for Patient Organizations Based on US and European Experience

Practical Application | [Open access](#) | [Published: 22 March 2023](#)

Volume 16, pages 183–199, (2023) [Cite this article](#)

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ECRD Poster

In 2022 we displayed our first poster at a Rare Disease Conference. Events like this are a great way to raise awareness of Poland Syndrome with health care professionals, researchers and clinicians. In turn this helps us to build relationships with health care professionals and researchers that want to help us with our mission to improve the diagnosis and treatment of Poland Syndrome.

You can check out the poster here: <https://api.ltb.io/show/ABNBT>

Its thanks to the Poland Syndrome communities engagement with the register that has led to this opportunity, so thank you all for getting involved. Thanks to Pulse Infoframe Inc. for creating the poster too.

#ECRD2022 is the 11th edition of the European Conference on Rare Diseases and Orphan Products (ECRD) 2022, taking place over five days from Monday, 27th June to Friday 1st July.

Leading, inspiring and engaging all stakeholders to take action, the Conference is an unrivalled opportunity to network and exchange invaluable knowledge with hundreds of stakeholders in the rare disease community – patient advocates, policy makers, researchers, clinicians, healthcare professionals, healthcare industry representatives, academics, payers, regulators and Member State representatives.

The rapid deployment of a rare disease community registry

Fillingham, S¹; Henderson, J²; Liu, N², Gwadry-Sridhar, F²
¹PIP-UK, UK; ²Pulse Infoframe, USA



The rapid deployment of a rare disease community registry

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INTRODUCTION

Poland Syndrome is a rare birth difference that occurs during foetal development where the baby is born with physical differences. It is estimated to affect 1 in 20,000 newborns and there are currently no effective treatments.

PIP-UK is a registered charity in England and Wales that was established to support and the Poland Syndrome community. For the last 10 years PIP-UK has been conceptualizing and planning a patient registry project to overcome the issues of disparate data, globally dispersed.

OBJECTIVES

To answer this challenge, PIP-UK was focused on ensuring that the data were collected in a standardized way, met regulatory requirements and aligned with their vision to build global collaboration, with the technology as a nucleus for patients to convene and share their experiences.

METHODS

PIP-UK started working with Pulse Infoframe in 2021 to launch the Poland Syndrome Community Register. Utilising the Pulse Platform, PIP-UK were able to deploy the registry within 4 months with a recruitment target of 100 participants in the first 3 months.

Common data elements to form the central hub for data to be characterized and curated were created. PIP-UK and Pulse addressed the regulatory requirements that would be needed for drug development by ensuring that the data are collected in a platform that adheres to FDA and EMA data standards and further provides confidence to participants that their data are stored safely due to compliance with HIPAA and GDPR.

RESULTS

The registry currently has 147 active participants enrolled into the platform where 48% of them are under the age of 10. The oldest participants are over the age of 80 years old. Over 40% of participants are received a diagnosis of Poland Syndrome from their surgeon, while only 13% received their diagnosis from a GP.

Figure 1. Age at diagnosis

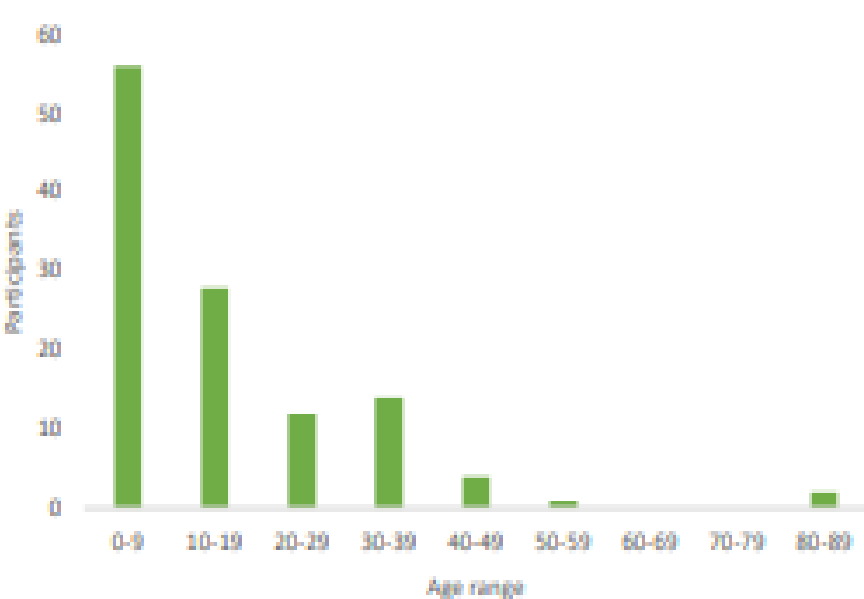
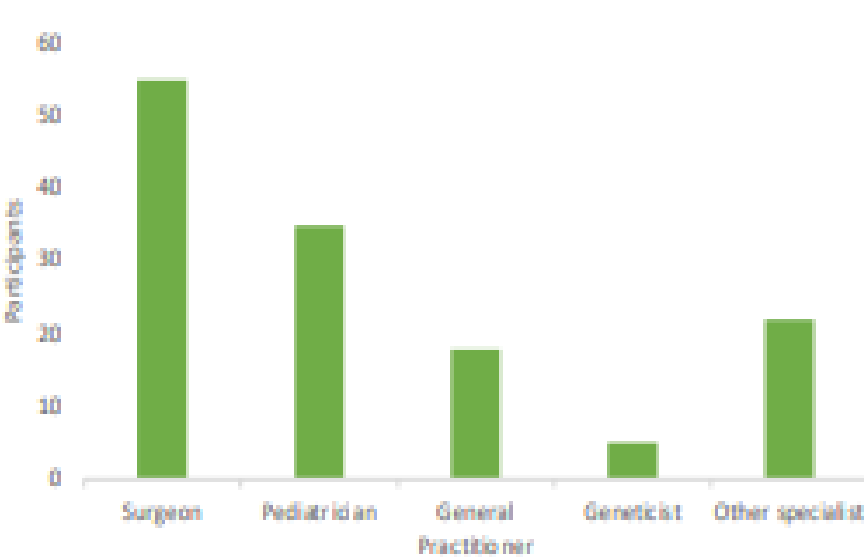


Figure 2. Diagnosis physician



CONCLUSIONS

With advocacy's commitment and leadership PIP-UK has illustrated how a rare disease community can come together from all around the world and collaborate with other stakeholders so that research into their condition can be advanced in using scientific methodology.

PIP-UK in Scotland



We have had amazing support in Scotland since our early days. Our members and volunteers in Scotland are growing and growing. So much so we took the step to register as a charity in Scotland in 2023. Our OSCR reference number is Scottish Charity Regulator SC052305.

Robbie Woods and family have been phenomenal fundraisers since 2018. In 2022 Robbie and his brother-in-law Joe took on a Tough Mudder and raised a fantastic £1153.75.

On the same weekend we held a meet up for our Scottish members in Dumfries. We met lots of new families and spent some lovely time getting to know each other and share experiences, information and support.



PIP-UK in Scotland



Our Scottish members and supporters kept on growing and we were supported by an amazing fundraiser and awareness campaign from new volunteer Jen Mellin and Family in January 2023 in honour of Jens mum's birthday. Raising a phenomenal £2,985. Jen quickly became a fierce advocate for Poland Syndrome in Scotland, raising awareness and volunteering with PIP-UK, so much so 2024 saw the launch of the Scotland Branch of PIP-UK.

Jen received an overwhelming and unprecented response from local and national press in Scotland to raise awareness of Poland Syndrome. Increasing our membership base in Scotland and building relationship with Scottish Parliament, Office for Rare Conditions and Glasgow Childrens Hospital. We could not be happier to have Jen on Team PIP-UK leading the charge in Scotland and we know there is lots to come from this incredible volunteer.



GLASGOWLIVE.CO.UK

Lanarkshire baby born with missing chest muscle and webbed finger diagnosed with rare condition



PIP-UK in Scotland



Our volunteer Kelly came to our meet up in Dumfries and after the event, seeing the impact PIP-UK as for her and other, Kelly was determined to make a difference in raising awareness of Poland Syndrome in Scotland. Kelly embarked on an awareness campaign to write to every GP in Scotland and inform them about Poland Syndrome and PIP-UK

The letters have been designed to raise awareness of Poland Syndrome and make sure GPs know about PIP-UK, so no-one is left alone when they are looking for support. Letters are on their way to Fort William, Aberdeen, Elgin, Wick, Benbecula, Aberfeldy, Isle of Jura, Dundee, Bells hill, Shetland island, Edinburgh to begin with. to have a ripple affect of awareness and reach in Scotland to this day.



PIP-UK in Scotland



Kelly personalised each letter, here's an excerpt to give you a flavour.

"My name is Kelly. I am a volunteer for PIP-UK...I was born with Poland Syndrome in 1979. I am left side affected, I have no chest muscles, shorter arm, underdeveloped hand and fingers also my body is slightly asymmetrical. I've had 2 tissue expanders, 4 breast implant operations on the left breast, a small implant and an uplift on the right breast. The implants keep folding so end up having to come out now my surgeon wants to start from scratch and do fat transfer. This caused me a lot of stress and had a detrimental effect on my mental health. I asked my surgeon if there was any support groups for Poland Syndrome and she told me no. This obviously isn't true as I found PIP-UK. It is very hard to live with a rare disease especially when it affects you 24/7. It's like living with a secret that you can't talk about due to embarrassment and no one understands because you think you are the only one born like that. My goal is to change that by finding others like myself to support so if you have a patient or know of anyone who has PS or has a family member with this rare birth condition could you please pass on our details as I would really love to hear from them. Could you please help me spread awareness by putting up my poster in your waiting room"



PIP-UK is so grateful to Kelly for all the hard work and personal resources she put into this campaign. The impact on the people reached is hard to quantify but continues to have a ripple affect of awareness and reach in Scotland to this day.



Poland Syndrome Clinic

Established in 2021, the Poland Syndrome Clinic at Birmingham Women and Childrens Hospital has gone from strength to strength. The doctors are building a specialism in Poland Syndrome diagnosis and treatment for Poland Syndrome which is the first of its kind in the UK.

Our mission to provide essential appointments and tests for families in need has been made possible through the support of Birmingham Children's Hospital. They have generously offered their invaluable NHS time to make this vision a reality, but they looked to us to guide and support families in finding the clinic. Without hesitation, we embraced this opportunity with enthusiasm. This is the only clinic in the UK for children with Poland Syndrome, families are travelling hundreds of miles to get the answers and medical assistance that cannot be found anywhere else.

Since 2021, we've had the privilege of overseeing ten clinics, providing essential appointments and tests for 50+ families. But our work extends beyond these appointments; we offer unwavering assistance in securing appointments through correspondence with GPs, and we stand by these families before, during, and after their clinic visits.

We are working with the hospital and the local MP to find a pathway to fund this clinic's resources long term. The waiting list is now over 12 months long due to the overwhelming need. While the community rallied to raise funds to support the clinic services, we now face a substantial financial gap. We have worked tirelessly to apply for funding since 2021 for this clinic and continue to do so, whilst also working on community fundraising campaigns.





Our Impact 2023



**6 POLAND
SYNDROME
CLINICS**

**30 CHILDREN
& FAMILIES
VISITED THE
CLINIC FOR
TREATMENT
&
DIAGNOSIS**






Our Community Fundraisers

2022-2023 is the year that our community united in raising more money for the benefit of the PIP-UK Poland Syndrome Community than ever before. An amazing £13,755 was raised by a number of major fundraisers and raffles. This community fundraising enable us to continue supporting more families than ever to access our children’s clinics, hold more events than ever before. This enabled us to increase the vital technical support for the first time, such as laptops, zoom & Microsoft subscriptions for our volunteers and CEO to reach and support more people than ever this year.

Special thanks goes to Natalie Barron, Stacey, Charmaine , Jen and Family and Robbie, Joe and Family.



View gallery

Change cover

304%

£304

raised of £100 target by 18 supporters

Give Now

Share

PIP-UK Poland Syndrome Charity

Stacey's Kielder Half Marathon for Poland Syndrome


Poland Syndrome Appeal
run by PIP-UK Poland Syndrome Charity
We empower & support people with Poland Syndrome to live well

What is Poland Syndrome?

01

Poland Syndrome

Poland Syndrome is a rare birth difference. It occurs during foetal development and the baby is born with physical differences on one side of the body.



Watch on

YouTube

1370%

£2,740

raised of £200 target by 27 supporters

Give Now

Share

PIP-UK Poland Syndrome Charity


Charmaine's 70th Fundraiser

Fundraising for PIP-UK Poland Syndrome Charity

Poland Syndrome Appeal
Campaign by PIP-UK Poland Syndrome Charity (RCN 1188941)

We empower & support people with Poland Syndrome to live well providing 121 support, advocacy, wellbeing programmes, early diagnosis help, peer support, ways to connect.
We need your help to continue this work and

/charmaine70/admin/edit the birthday of Charmaine Johnston 19 January 2023



View gallery

Change cover

102%

£1,029

raised of £1,000 target by 28 supporters

Give Now

Share

PIP-UK Poland Syndrome Charity

Robbie & Joes Tough Mudder 10k Scotland

Poland Syndrome Appeal
run by PIP-UK Poland Syndrome Charity
We empower & support people with Poland Syndrome to live well



Our Grant Funders

2022-2023 is the year that our grant support increased to support the increase in demand on our services and to meet the needs of our growing community. All of the work to support our beneficiaries is only possible with the kind support of these grant giving organisations.










Special thanks goes to The National Lottery, Arnold Clark, Forever Manchester CDL Fund, Maryland Trust, The Souter Family Trust.














Our Volunteers and Board

2022-2023 saw our volunteer numbers and board grow significantly. Enabling us to host more events than ever before as well as support more community members to meet the increasing demand. We are proud that our board is made of 100% of people with lived experience of Poland Syndrome including people with Poland Syndrome and parents and grandparents of children with Poland Syndrome. This growth continues in 2023-2024.

								
Angel Chair	Victoria Treasurer	Julie Secretary	Liz Trustee	Shirley Trustee	Robbie Trustee	Kira Trustee	Paul Trustee	Peter Trustee

The Board

								
Ron	Kelly	Jen	David	Polina	Becki	Adrian	Michelle	Giselle

Our Volunteers

PIP-UK

PIP Parents Information Portal

Charity No. 1188941

Trustees' Report and Unaudited Accounts

31 March 2023

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Trustees' Annual Report	2
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Statement of Financial Activities	4
Balance Sheet	5
Notes to the Accounts	6 to 12
Detailed Statement of Financial Activities	13 to 14

The trustees present their report with the unaudited financial statements of the charity for the year ended 31 March 2023.

REFERENCE AND ADMINISTRATIVE DETAILS

Charity No. 1188941

Trustees

The following trustees served during the year:

K. Aspland

P. Bannister

V. Bedwell

J. Erasmus

E. McKenna

P. Preston

S.B. Proctor

A. Scott-Bottoms

R. Woods

Accountants

Solutions Accountancy & Bookkeeping Ltd

1 The Mews

Little Brunswick Street

Huddersfield

HD1 5JL

OBJECTIVES AND ACTIVITIES, ACHIEVEMENTS AND PERFORMANCE & PLANS FOR FUTURE PERIODS.

Refer to Trustee Annual Report.

Statement of trustees' responsibilities in relation to the financial statements

The charity trustees are responsible for preparing a trustees' annual report and financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011, the applicable Charities (Accounts and Reports) Regulations, and the provisions of the Trust deed. The Trustees are also responsible for safeguarding the assets of the charity and hence taking reasonable steps for the prevention and detection of fraud and other irregularities.

Signed on behalf of the charity's trustees


Paul Preston (Nov 20, 2023 18:17 GMT)

P. Preston

Trustee

17 November 2023

Independent Examiner's Report to the trustees of PIP Parents Information Portal

I report to the trustees on my examination of the financial statements of PIP Parents Information Portal for the year ended 31 March 2023 which comprise the Statement of Financial Activities, the Balance Sheet and the related notes.

Responsibilities and basis of report

As the charity's trustees you are responsible for the preparation of the financial statements in accordance with the requirements of the Charities Act 2011('the Act'). The trustees consider that an audit is not required for this year under the Charities Act 2011, s.144(2) (the 2011 Act) and that an independent examination is needed.

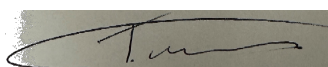
I report in respect of my examination of the charity's financial statements carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I can 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:

- the accounting records were not kept in respect of the charity as required by section 130 of the Act; or
- the financial statements do not accord with those records; or
- the financial statements do not comply with the applicable requirements concerning the form and content of the financial statements set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the financial statements 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 financial statements to be reached.



CPAA
Solutions Accountancy & Bookkeeping Ltd
1 The Mews
Little Brunswick Street
Huddersfield

HD1 5JL
17 November 2023

PIP Parents Information Portal
Statement of Financial Activities
for the year ended 31 March 2023

		Unrestricted funds 2023 £	Restricted funds 2023 £	Total funds 2023 £	Total funds 2022 £
	Notes				
Income and endowments from:					
Donations and legacies	3	27,393	15,700	43,093	27,525
Other trading activities	4	1,357	-	1,357	3,184
Investments	5	5	-	5	6
Other	6	-	-	-	552
Total		28,755	15,700	44,455	31,267
Expenditure on:					
Raising funds	7	1,022	-	1,022	6,426
Charitable activities	8	9,523	-	9,523	745
Other	9	25,845	12,000	37,845	29,270
Total		36,390	12,000	48,390	36,441
Net gains on investments		-	-	-	-
Net expenditure	10	(7,635)	3,700	(3,935)	(5,174)
Transfers between funds		-	-	-	-
Net expenditure before other gains/(losses)		(7,635)	3,700	(3,935)	(5,174)
Other gains and losses					
Net movement in funds		(7,635)	3,700	(3,935)	(5,174)
Reconciliation of funds:					
Total funds brought forward		13,360	-	13,360	18,534
Total funds carried forward		5,725	3,700	9,425	13,360

at 31 March 2023

Charity No. 1188941

		2023 £	2022 £
Fixed assets			
Tangible assets	12	287	-
		<u>287</u>	<u>-</u>
Current assets			
Debtors	13	3,005	4,644
Cash at bank and in hand		7,074	9,496
		<u>10,079</u>	<u>14,140</u>
Creditors: Amount falling due within one year	14	(941)	(780)
Net current assets		<u>9,138</u>	<u>13,360</u>
Total assets less current liabilities		<u>9,425</u>	<u>13,360</u>
Net assets excluding pension asset or liability		<u>9,425</u>	<u>13,360</u>
Total net assets		<u><u>9,425</u></u>	<u><u>13,360</u></u>
The funds of the charity			
Restricted funds	15		
Restricted income funds		3,700	-
		<u>3,700</u>	<u>-</u>
Unrestricted funds	15		
General funds		5,725	13,360
		<u>5,725</u>	<u>13,360</u>
Reserves	15		
Total funds		<u><u>9,425</u></u>	<u><u>13,360</u></u>

Approved by the trustees on 17 November 2023

And signed on their behalf by:

Paul Preston

Paul Preston (Nov 20, 2023 18:17 GMT)

P. Preston

Trustee

17 November 2023

for the year ended 31 March 2023

1 Accounting policies

Basis of preparation

The financial statements have been prepared in accordance with 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 and the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102) and the Charities Act 2011.

Change in basis of accounting or to previous accounts

There has been no change to the accounting policies (valuation rules and method of accounting) since last year and no changes have been made to accounts for previous years.

Fund accounting

Unrestricted funds	These are available for use at the discretion of the trustees in furtherance of the general objects of the charity.
Designated funds	These are unrestricted funds earmarked by the trustees for particular purposes.
Revaluation funds	These are unrestricted funds which include a revaluation reserve representing the restatement of investment assets at their market values.
Restricted funds	These are available for use subject to restrictions imposed by the donor or through terms of an appeal.

Income

Recognition of income	Income is included in the Statement of Financial Activities (SoFA) when the charity becomes entitled to, and virtually certain to receive, the income and the amount of the income can be measured with sufficient reliability.
-----------------------	---

Income with related expenditure	Where income has related expenditure the income and related expenditure is reported gross in the SoFA.
---------------------------------	--

Donations and legacies	Voluntary income received by way of grants, donations and gifts is included in the the SoFA when receivable and only when the Charity has unconditional entitlement to the income.
------------------------	--

Tax reclaims on donations and gifts	Income from tax reclaims is included in the SoFA at the same time as the gift/donation to which it relates.
-------------------------------------	---

Donated services and facilities	These are only included in income (with an equivalent amount in expenditure) where the benefit to the Charity is reasonably quantifiable, measurable and material.
---------------------------------	--

Volunteer help	The value of any volunteer help received is not included in the accounts.
----------------	---

Investment income	This is included in the accounts when receivable.
-------------------	---

Gains/(losses) on revaluation of fixed assets	This includes any gain or loss resulting from revaluing investments to market value at the end of the year.
---	---

Gains/(losses) on investment assets	This includes any gain or loss on the sale of investments.
-------------------------------------	--

Notes to the Accounts

Expenditure

Recognition of expenditure	Expenditure is recognised on an accruals basis. Expenditure includes any VAT which cannot be fully recovered, and is reported as part of the expenditure to which it relates.
Expenditure on raising funds	These comprise the costs associated with attracting voluntary income, fundraising trading costs and investment management costs.
Expenditure on charitable activities	These comprise the costs incurred by the Charity in the delivery of its activities and services in the furtherance of its objects, including the making of grants and governance costs.
Grants payable	All grant expenditure is accounted for on an actual paid basis plus an accrual for grants that have been approved by the trustees at the end of the year but not yet paid.
Governance costs	These include those costs associated with meeting the constitutional and statutory requirements of the Charity, including any audit/independent examination fees, costs linked to the strategic management of the Charity, together with a share of other administration costs.
Other expenditure	These are support costs not allocated to a particular activity.

Taxation

The charity is exempt from tax on its charitable activities.

Tangible fixed assets and depreciation

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life:

Fixtures, Fittings and Equipment	25% Straight Line
----------------------------------	-------------------

Trade and other debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

Cash and cash equivalents

Cash and cash equivalents comprise cash at bank and on hand, demand deposits with banks and other short-term highly liquid investments with original maturities of three months or less and bank overdrafts. In the statement of financial position, bank overdrafts are shown within borrowings or current liabilities. In the Statement of Cash Flows, cash and cash equivalents are shown net of bank overdrafts that are repayable on demand and form an integral part of the company's cash management.

Trade and other creditors

Short term creditors are measured at the transaction price. Other creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

Pension costs

The charity operates a defined contribution plan for its employees. A defined contribution plan is a pension plan under which the charity pays fixed contributions into a separate entity. Once the contributions have been paid the charity has no further payments obligations. The contributions are recognised as expenses when they fall due. Amounts not paid are shown in accruals in the balance sheet. The assets of the plan are held separately from the charity in independently administered funds.

Receipt of donated goods, facilities and services

All donated goods, facilities and services received are recognised within incoming resources and expenditure at an estimate of the value to the charity.

2 Statement of Financial Activities - prior year

	Unrestricted funds 2022 £	Restricted funds 2022 £	Total funds 2022 £
Income and endowments from:			
Donations and legacies	11,210	16,315	27,525
Other trading activities	3,184	-	3,184
Investments	6	-	6
Other	552	-	552
Total	14,952	16,315	31,267
Expenditure on:			
Raising funds	6,426	-	6,426
Charitable activities	745	-	745
Other	12,955	16,315	29,270
Total	20,126	16,315	36,441
Net income	(5,174)	-	(5,174)
Net income before other gains/(losses)	(5,174)	-	(5,174)
Other gains and losses:			
Net movement in funds	(5,174)	-	(5,174)
Reconciliation of funds:			
Total funds brought forward	18,534	-	18,534
Total funds carried forward	13,360	-	13,360

3 Income from donations and legacies

	Unrestricted £	Restricted £	Total 2023 £	Total 2022 £
Donations	12,393	-	12,393	1,210
Grants receivable	15,000	15,700	30,700	26,315
	27,393	15,700	43,093	27,525

4 Income from other trading activities

Unrestricted	Total 2023	Total 2022
£	£	£
Fund raising events	1,357	3,184
<u>1,357</u>	<u>1,357</u>	<u>3,184</u>

5 Income from investments

Unrestricted	Total 2023	Total 2022
£	£	£
Bank interest receivable	5	6
<u>5</u>	<u>5</u>	<u>6</u>

6 Other income

Total 2023	Total 2022
£	£
-	552
<u>-</u>	<u>552</u>

7 Expenditure on raising funds

Unrestricted	Total 2023	Total 2022
£	£	£
<i>Costs of generating voluntary income</i>		
Donations	203	625
Advertising & marketing	43	1,620
<i>Fundraising trading costs</i>		
Fund raising events	776	4,181
<u>1,022</u>	<u>1,022</u>	<u>6,426</u>

8 Expenditure on charitable activities

Unrestricted	Total 2023	Total 2022
£	£	£
<i>Expenditure on charitable activities</i>		
Register software costs	8,630	-
<i>Governance costs</i>		
Governance costs	893	745
<u>9,523</u>	<u>9,523</u>	<u>745</u>

9 Other expenditure

	Unrestricted	Restricted	Total 2023	Total 2022
	£	£	£	£
Employee costs	21,849	12,000	33,849	28,129
Motor and travel costs	1,844	-	1,844	185
Amortisation, depreciation, impairment, profit/loss on disposal of fixed assets	96	-	96	-
General administrative costs	1,796	-	1,796	956
Legal and professional costs	260	-	260	-
	<u>25,845</u>	<u>12,000</u>	<u>37,845</u>	<u>29,270</u>

10 Net expenditure before transfers

	2023	2022
	£	£
This is stated after charging:		
Depreciation of owned fixed assets	96	-
Independent Examiner's fee	780	780

11 Staff costs

	2023	2022
Salaries and wages	32,178	27,221
Pension costs	826	623
	<u>33,004</u>	<u>27,844</u>

No employee received emoluments in excess of £60,000.

12 Tangible fixed assets

	Fixtures, Fittings and Equipment £	Total £
Cost or revaluation		
Additions	383	383
At 31 March 2023	<u>383</u>	<u>383</u>
Depreciation and impairment		
Depreciation charge for the year	96	96
At 31 March 2023	<u>96</u>	<u>96</u>
Net book values		
At 31 March 2023	<u>287</u>	<u>287</u>

13 Debtors

	2023	2022
	£	£
Trade debtors	3,000	3,350
Other debtors	5	1,294
	<u>3,005</u>	<u>4,644</u>

14 Creditors:

amounts falling due within one year

	2023	2022
	£	£
Other taxes and social security	162	-
Accruals	779	780
	<u>941</u>	<u>780</u>

15 Movement in funds

	At 1 April 2022	Incoming resources (including other gains/losses) £	Resources expended £	At 31 March 2023 £
Restricted funds:				
Restricted income funds:				
The National Lottery				
Community Fund	-	10,000	(10,000)	-
Arnold Clark	-	2,000	(2,000)	-
Forever Manchester CDL				
Fund	-	700	-	700
The Souter Charitable Trust	-	3,000	-	3,000
<i>Total</i>	<u>-</u>	<u>15,700</u>	<u>(12,000)</u>	<u>3,700</u>
Unrestricted funds:				
General funds	13,360	13,755	(21,390)	5,725
Designated funds:				
Maryland Trust	-	15,000	(15,000)	-
<i>Total</i>	<u>-</u>	<u>15,000</u>	<u>(15,000)</u>	<u>-</u>
Total funds	<u>13,360</u>	<u>44,455</u>	<u>(48,390)</u>	<u>9,425</u>

Purposes and restrictions in relation to the funds:

Restricted funds:

The National Lottery	Living Well with PS
Community Fund	
Arnold Clark	Core Costs
Forever Manchester CDL	Living Well with PS
Fund	
The Souter Charitable Trust	Clinic Delivery

Designated funds:

Maryland Trust	PSCR Pilot
----------------	------------

16 Analysis of net assets between funds

	Unrestricted funds £	Restricted funds £	Total £
Fixed assets	287	-	287
Net current assets	6,138	3,000	9,138
	<u>6,425</u>	<u>3,000</u>	<u>9,425</u>

17 Reconciliation of net debt

	At 1 April 2022 £	Cash flows £	At 31 March 2023 £
Cash and cash equivalents	9,496	(2,422)	7,074
	<u>9,496</u>	<u>(2,422)</u>	<u>7,074</u>
Net debt	<u>9,496</u>	<u>(2,422)</u>	<u>7,074</u>

18 Commitments

Operating lease commitments

Annual commitments under non-cancellable operating leases are as follows:

	2023 Land and buildings £	2023 Other £	2022 Land and buildings £	2022 Other £
Operating leases with expiry date:				

Pension commitments

	2023 £	2022 £
The pension cost charge to the charity amounted to:	<u>826</u>	<u>623</u>

PIP Parents Information Portal
Detailed Statement of Financial Activities
for the year ended 31 March 2023

	Unrestricted funds 2023 £	Restricted funds 2023 £	Total funds 2023 £	Total funds 2022 £
Income and endowments from:				
Donations and legacies				
Donations	12,393	-	12,393	1,210
Grants receivable	15,000	15,700	30,700	26,315
	<u>27,393</u>	<u>15,700</u>	<u>43,093</u>	<u>27,525</u>
Other trading activities				
Fund raising events	1,357	-	1,357	3,184
	<u>1,357</u>	<u>-</u>	<u>1,357</u>	<u>3,184</u>
Investments				
Bank interest receivable	5	-	5	6
	<u>5</u>	<u>-</u>	<u>5</u>	<u>6</u>
Other				
	-	-	-	552
	<u>-</u>	<u>-</u>	<u>-</u>	<u>552</u>
Total income and endowments	28,755	15,700	44,455	31,267
Expenditure on:				
Costs of generating donations and legacies				
Donations	203	-	203	625
Advertising & marketing	43	-	43	1,620
	<u>246</u>	<u>-</u>	<u>246</u>	<u>2,245</u>
Costs of other trading activities				
Fund raising events	776	-	776	4,181
	<u>776</u>	<u>-</u>	<u>776</u>	<u>4,181</u>
Total of expenditure on raising funds	1,022	-	1,022	6,426
Charitable activities				
Register software costs	8,630	-	8,630	-
	<u>8,630</u>	<u>-</u>	<u>8,630</u>	<u>-</u>
Governance costs				
Governance costs	893	-	893	745
	<u>893</u>	<u>-</u>	<u>893</u>	<u>745</u>
Total of expenditure on charitable activities	9,523	-	9,523	745
Employee costs				
Salaries/wages	20,178	12,000	32,178	27,221
Pension costs	826	-	826	623
Staff training	845	-	845	285

PIP Parents Information Portal
Detailed Statement of Financial Activities

	21,849	12,000	33,849	28,129
Motor and travel costs				
Travel and subsistence	1,844	-	1,844	185
	1,844	-	1,844	185
General administrative costs, including depreciation and amortisation				
Depreciation of Fixtures, Fittings and Equipment	96	-	96	-
Bank charges	59	-	59	-
Equipment repairs and maintenance	19	-	19	-
General insurances	227	-	227	227
Postage and couriers	270	-	270	-
Software, IT support and related costs	622	-	622	227
Stationery and printing	169	-	169	176
Sundry expenses	398	-	398	326
Telephone, fax and broadband	32	-	32	-
	1,892	-	1,892	956
Legal and professional costs				
Consultancy fees	200	-	200	-
Other legal and professional costs	60	-	60	-
	260	-	260	-
Total of expenditure of other costs	25,845	12,000	37,845	29,270
Total expenditure	36,390	12,000	48,390	36,441
Net gains on investments	-	-	-	-
Net expenditure	(7,635)	3,700	(3,935)	(5,174)
Net expenditure before other gains/(losses)	(7,635)	3,700	(3,935)	(5,174)
Other Gains	-	-	-	-
Net movement in funds	(7,635)	3,700	(3,935)	(5,174)
Reconciliation of funds:				
Total funds brought forward	13,360	-	13,360	18,534
Total funds carried forward	5,725	3,700	9,425	13,360