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.

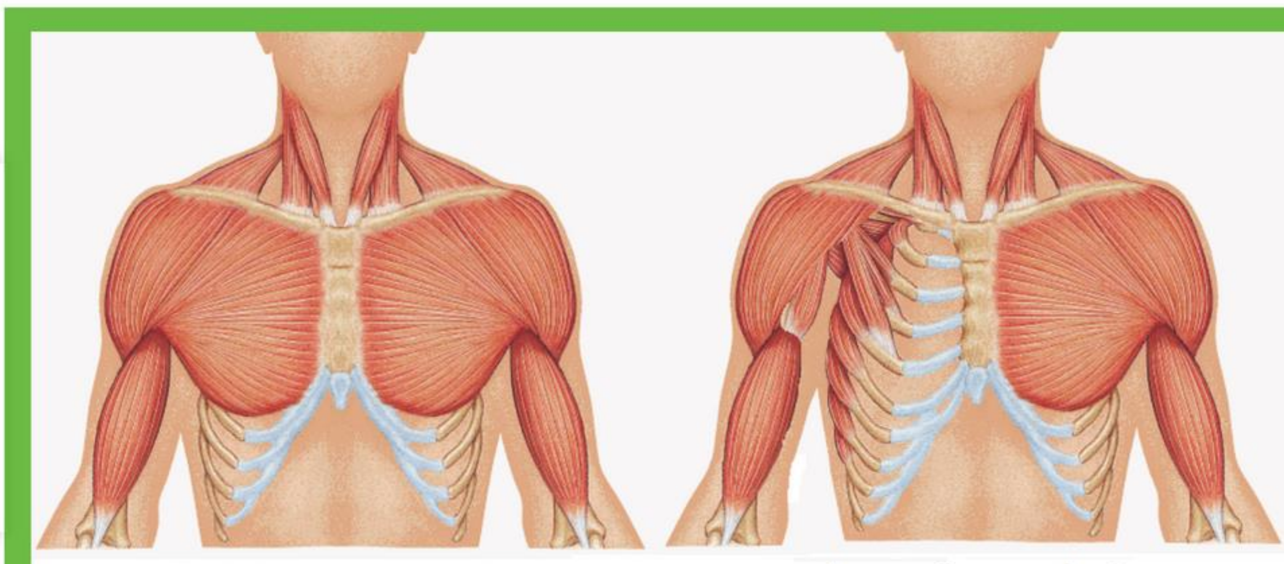
Goals

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

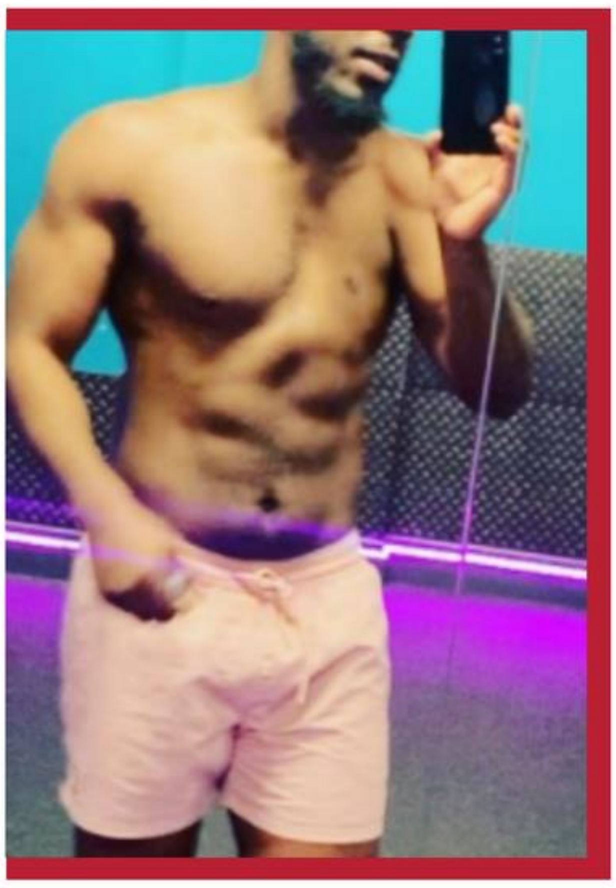
Poland Syndrome is a rare birth difference named after Dr Alfred Poland credited with its discovery

Chest Differences

01 80-99% OF PEOPLE WITH POLAND SYNDROME HAVE: ABSENT OR UNDERDEVELOPED:

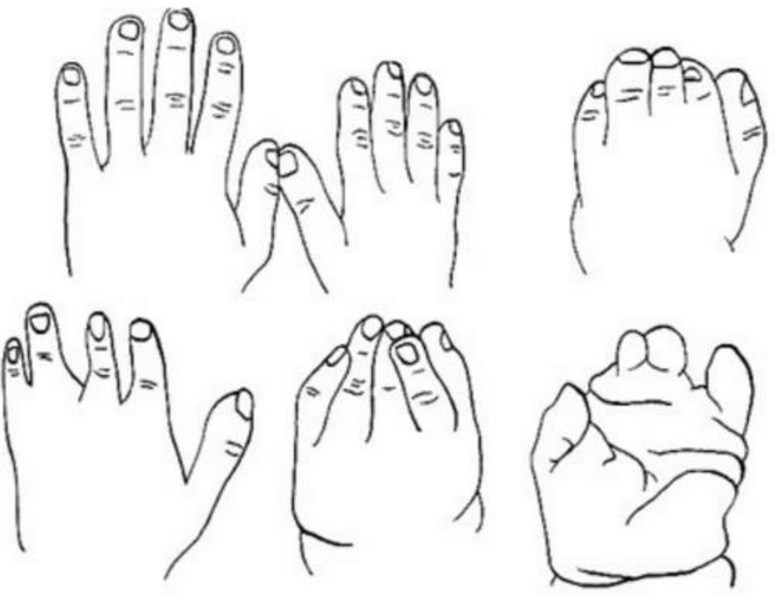
- CHEST MUSCLE
- BREAST
- NIPPLE

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 that 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.”

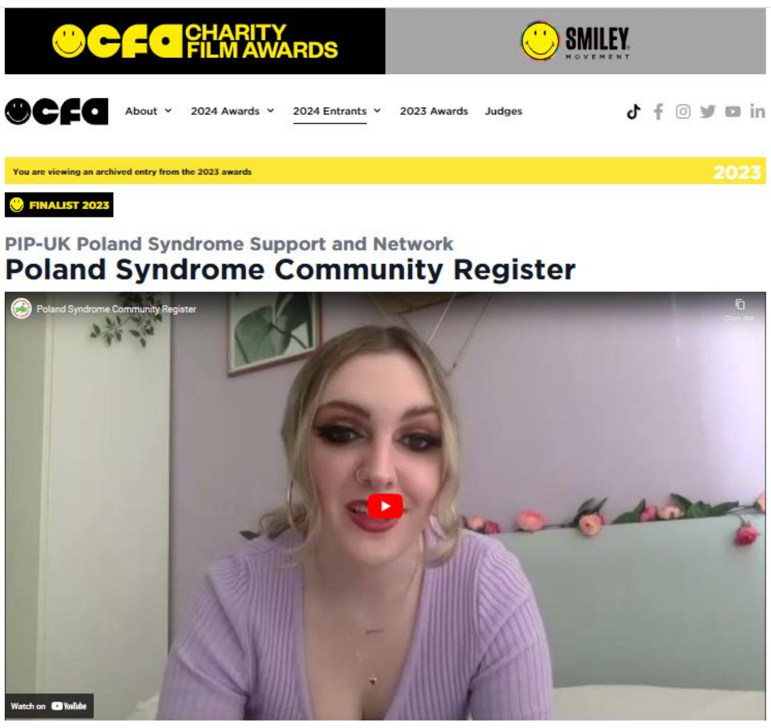
“Please consider funding these sessions again next year, as they make a huge difference in the wellbeing of us people living with Poland Syndrome, they're essential year on year!! Thank you”

“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



You are viewing an archived entry from the 2023 awards 2023

FINALIST 2023

PIP-UK Poland Syndrome Support and Network

Poland Syndrome Community Register

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.

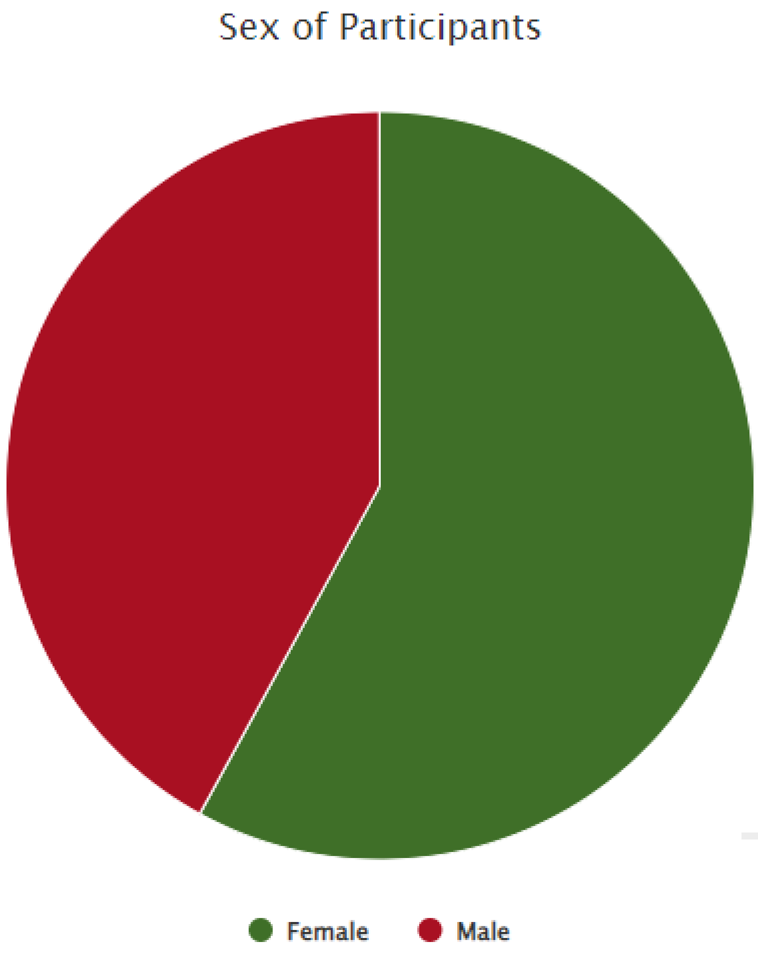
METHODS

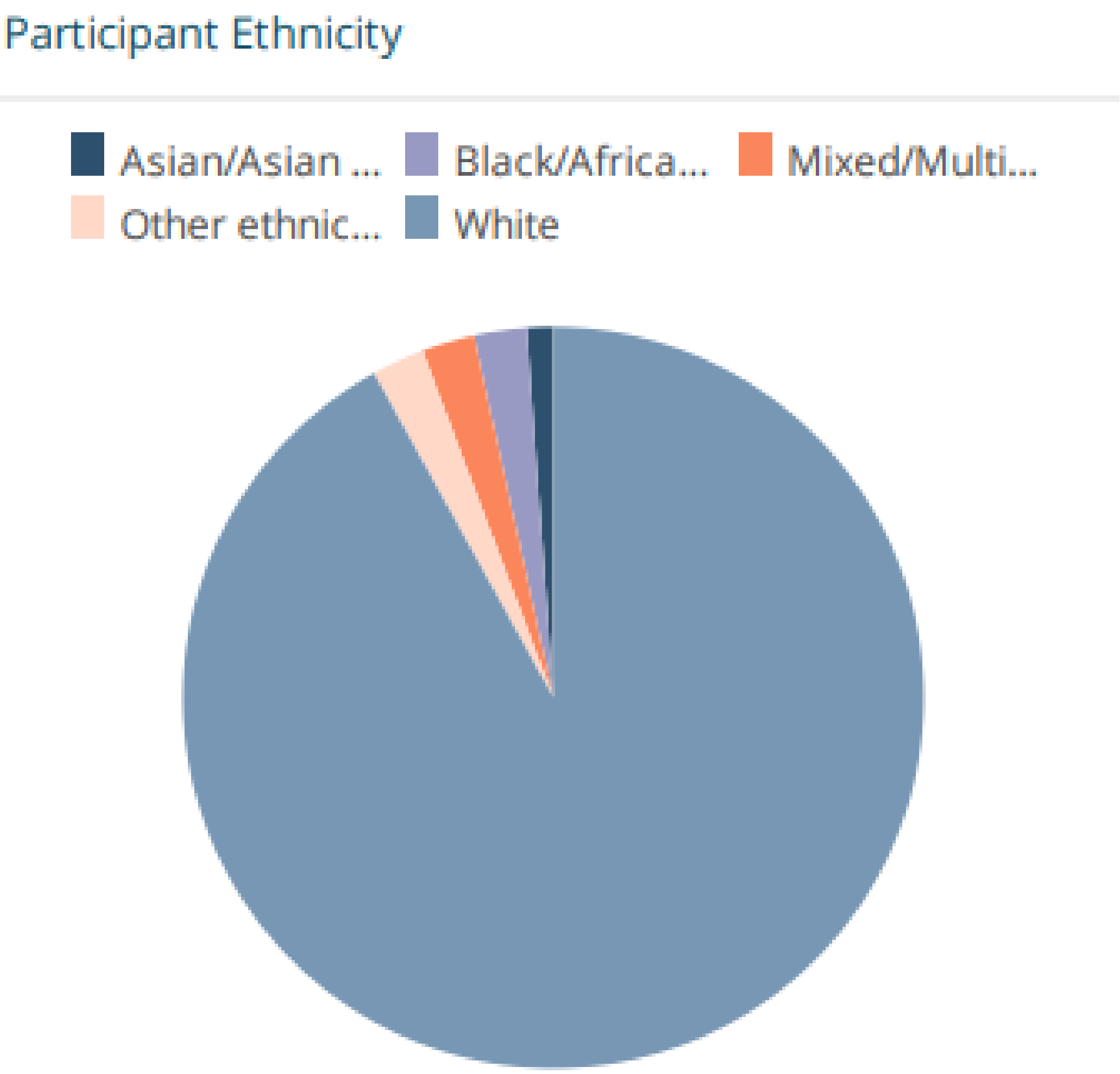
PIP-UK started working with Pulse Infoframe in 2021 to launch the Poland Syndrome Community Register. Utilising the Pulse Platform, PIP-UK were able to deploy the registry within 4 months with a recruitment target of 100 participants in the first 3 months. Common data elements to form the central hub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

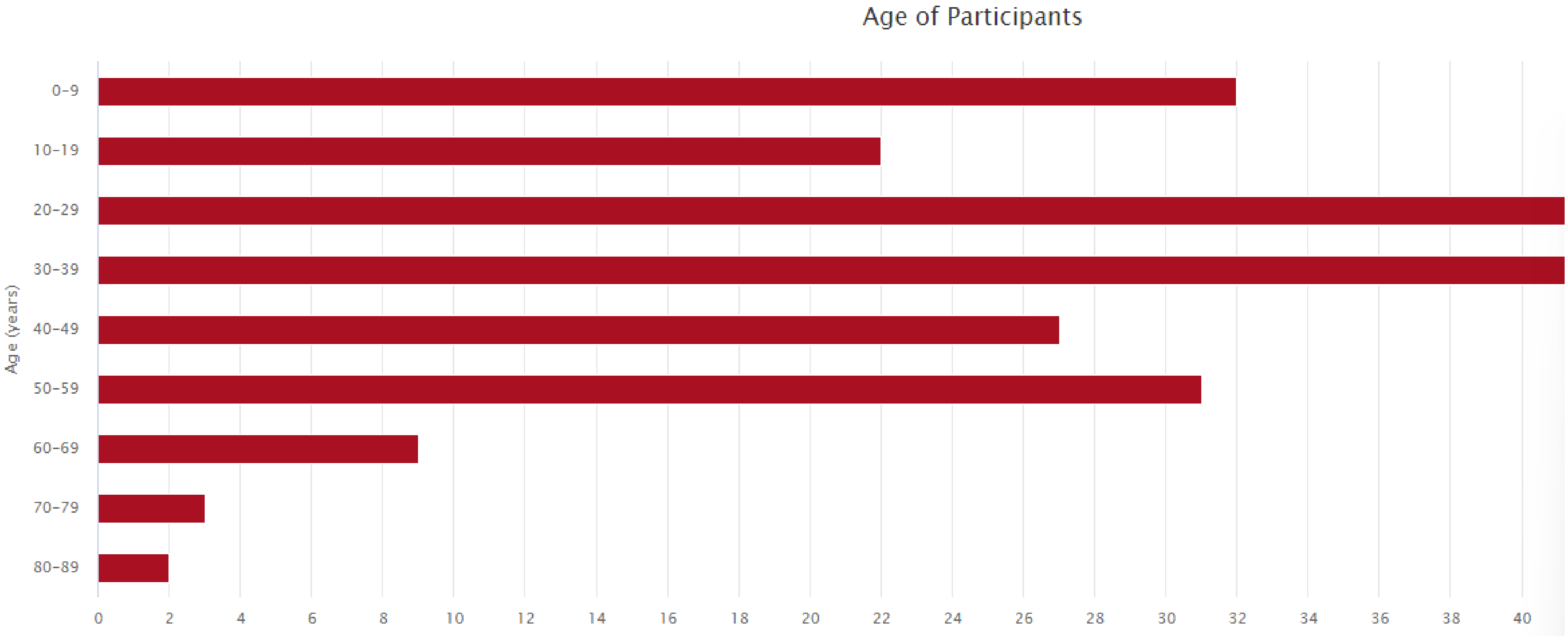
RESULTS SO FAR

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+.

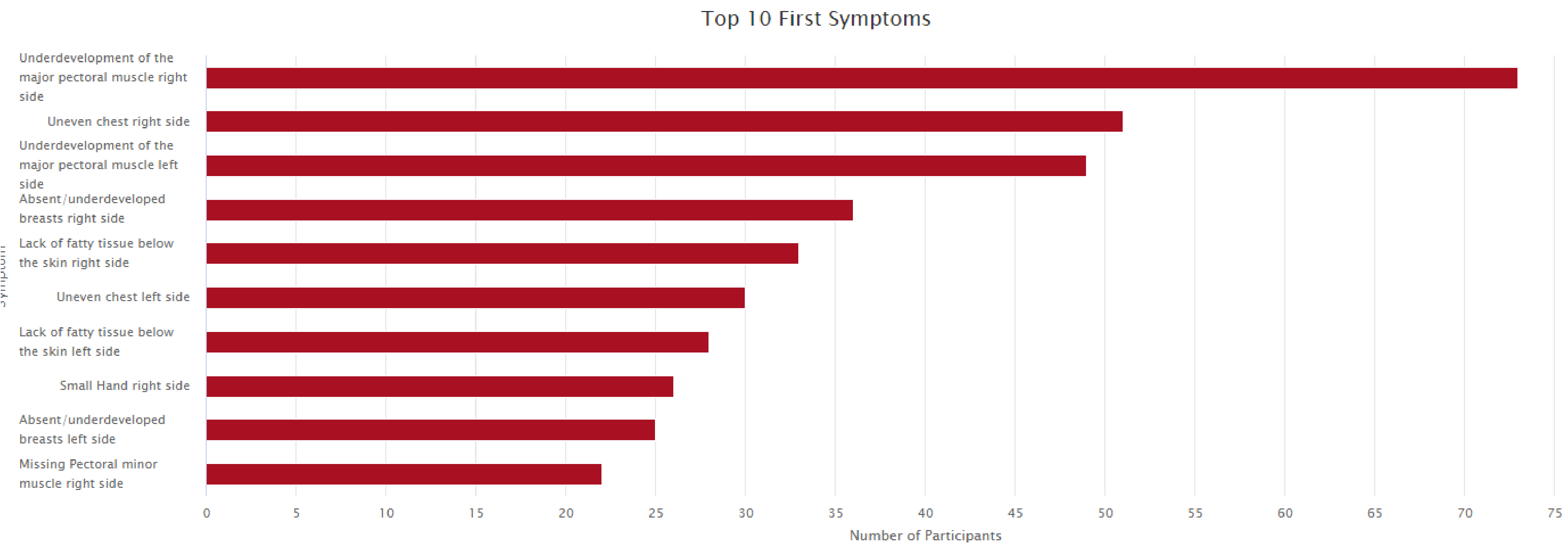
Poland Syndrome community register 2023

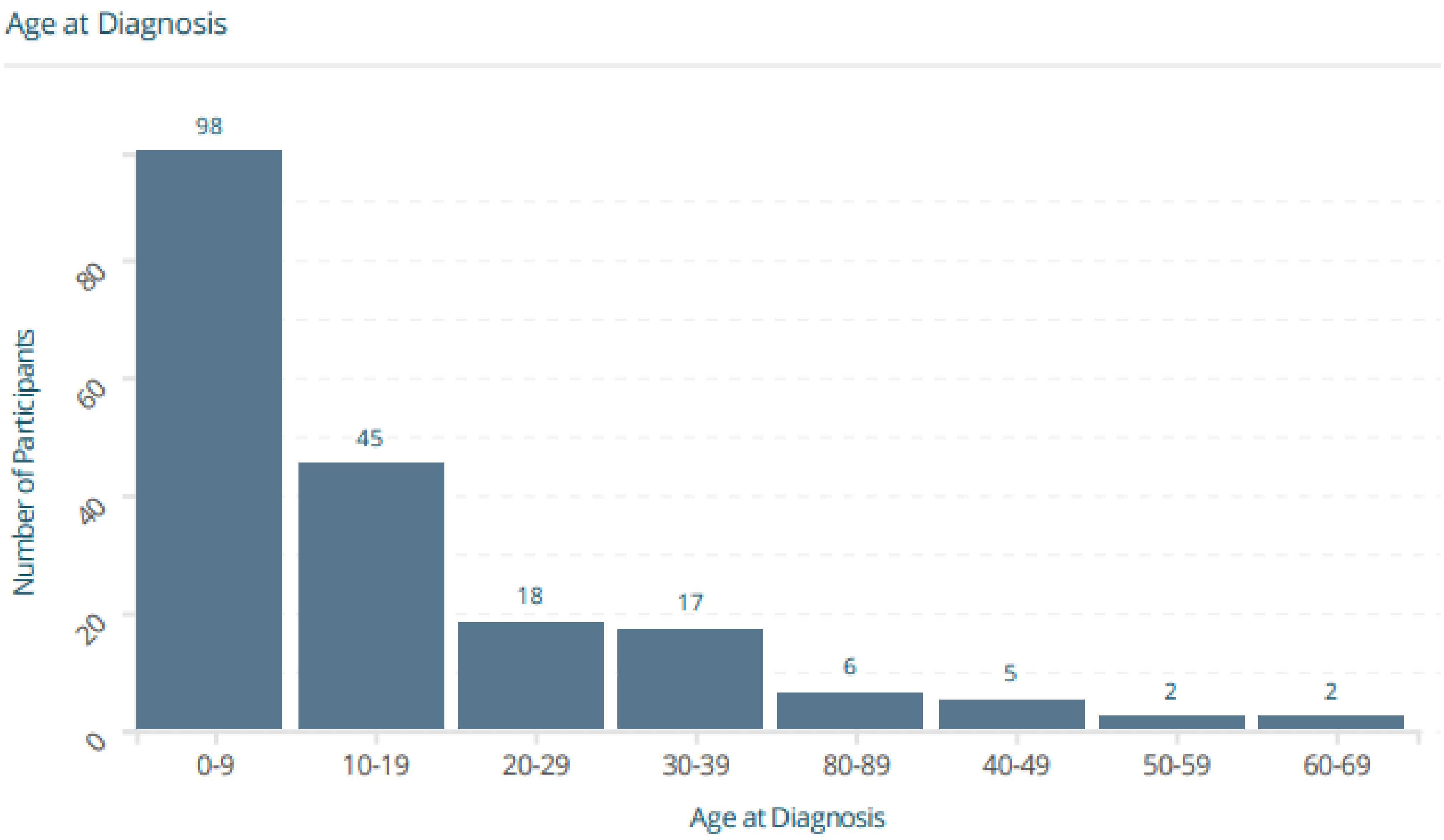






Poland Syndrome community register 2023





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

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

You have full access to this open access article

ECRD Poster

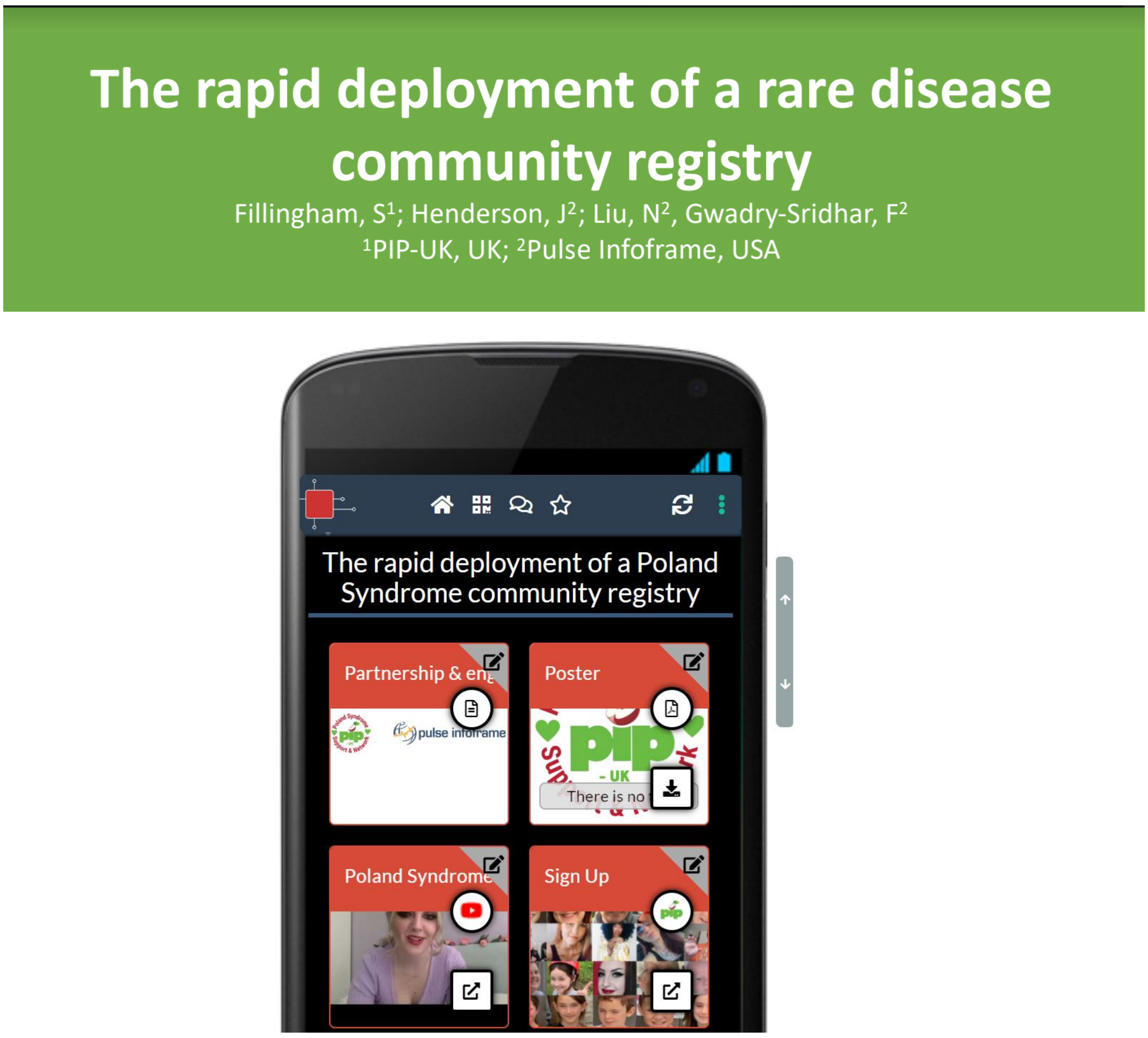
In 2022 we displayed our first poster at a Rare Disease Conference. Events like this are a great way to raise awareness of Poland Syndrome with health care professionals, researchers and clinicians. In turn this helps us to build relationships with health care professionals and researchers that want 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, S[1]; Henderson, J[2]; Liu, N[2], Gwadry-Sridhar, F[2]

[1]PIP-UK, UK; [2]Pulse Infoframe, USA

The rapid deployment of a Poland Syndrome community registry

ECRD Poster

The rapid deployment of a rare disease community registry

Fillingham, S[1]; Henderson, J[2]; Liu, N[2], Gwadry-Sridhar, F[2]
[1]PIP-UK, UK; [2]Pulse Infoframe, USA

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

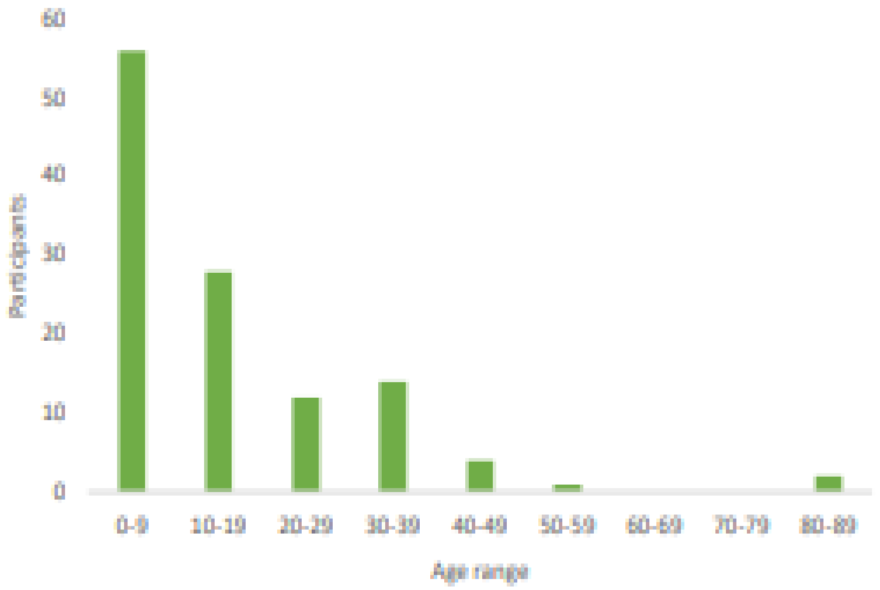
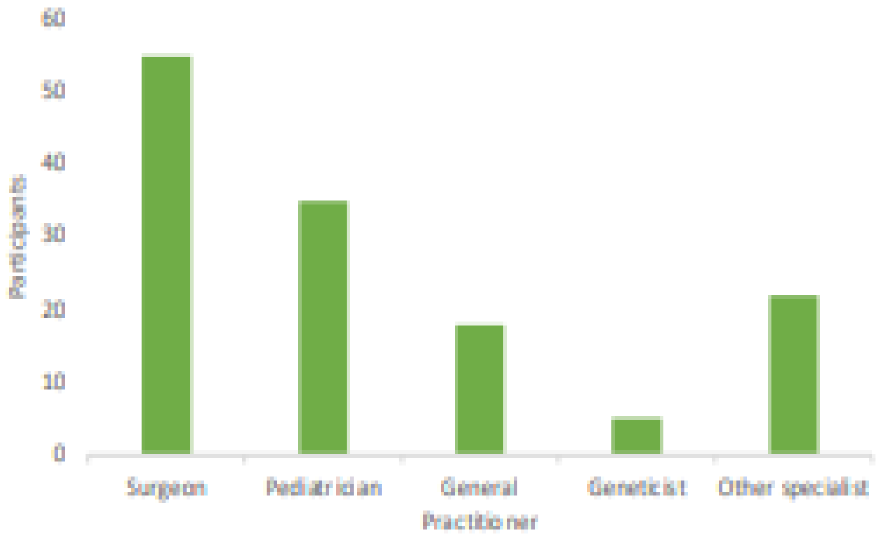


Figure 2. Diagnosis physician



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 in 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 clinics resources long term. The waiting list is now over 12 months long due 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

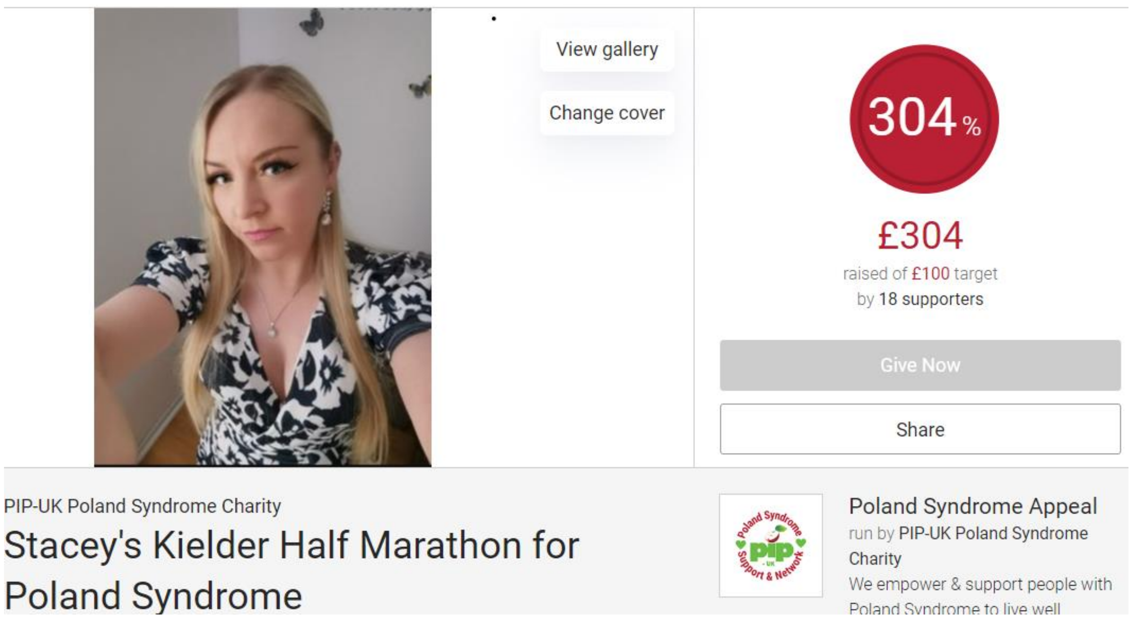
6 POLAND SYNDROME CLINICS

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.



£304

raised of £100 target

by 18 supporters

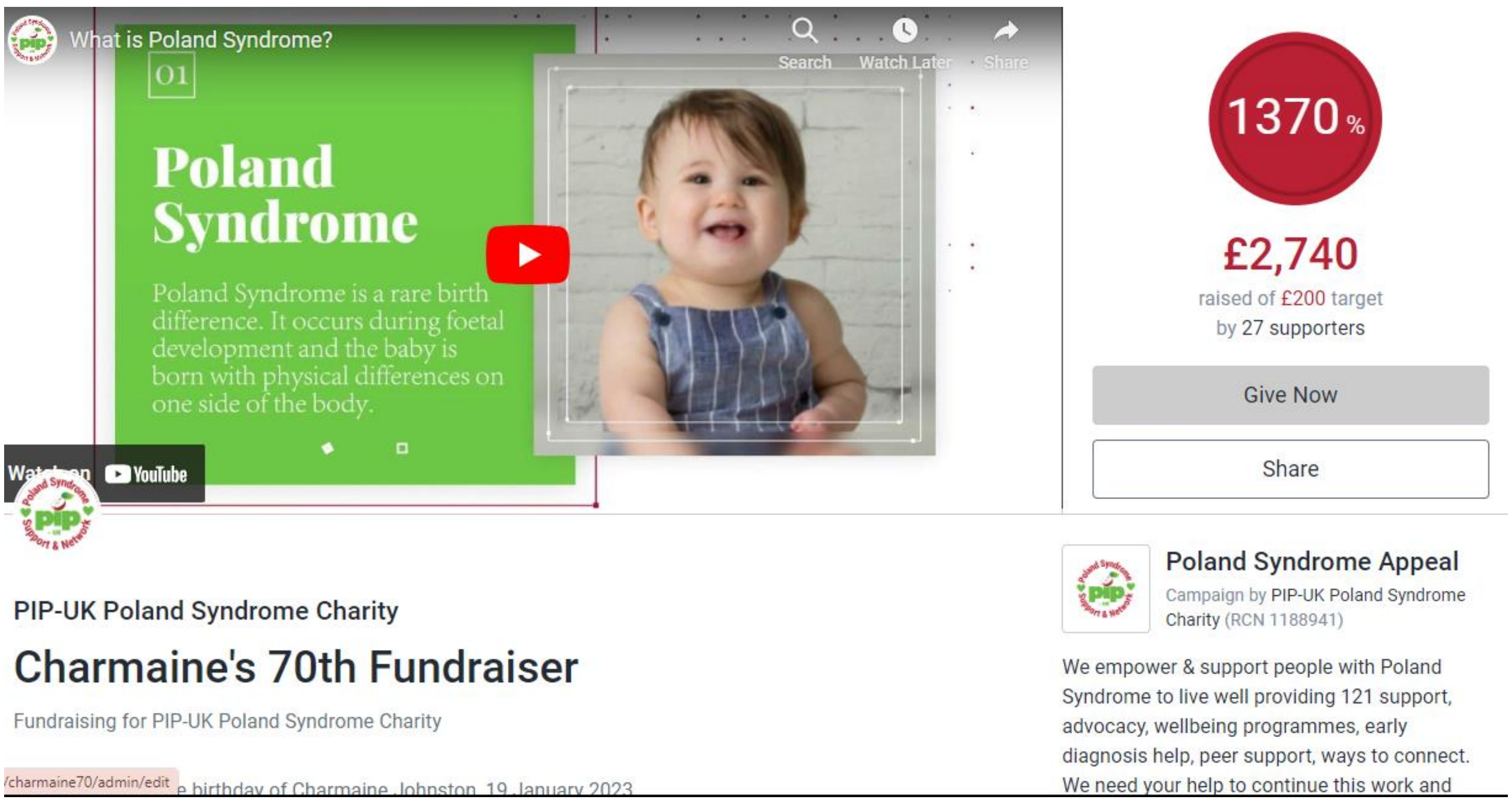
PIP-UK Poland Syndrome Charity

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



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.

£2,740

raised of £200 target

by 27 supporters

PIP-UK Poland Syndrome Charity

Charmaine's 70th Fundraiser

Fundraising for PIP-UK Poland Syndrome Charity

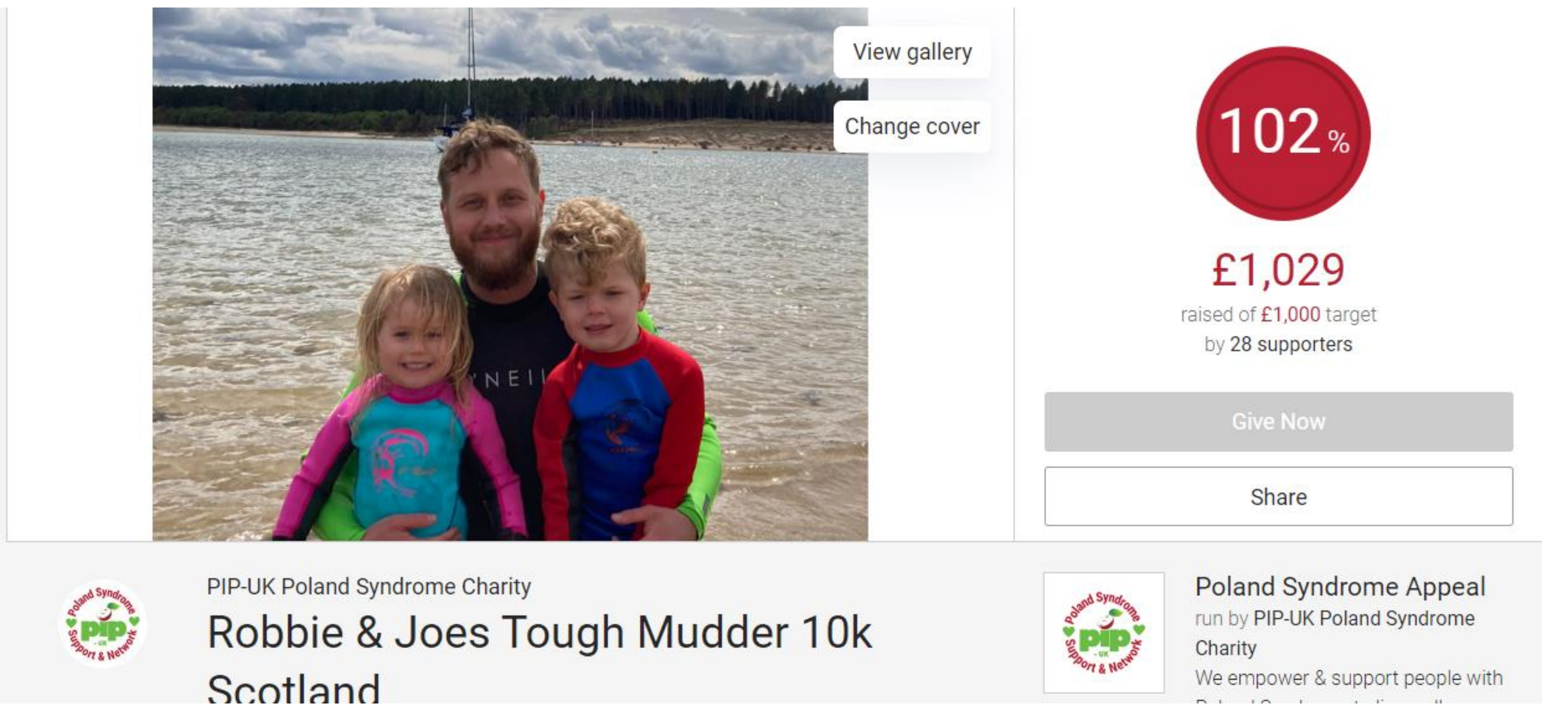
/charmaine70/admin/edit

e birthday of Charmaine Johnston 19 January 2023

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



£1,029

raised of £1,000 target

by 28 supporters

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

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.

COMMUNITY FUND

Arnold Clark COMMUNITY FUND

CDL FUND

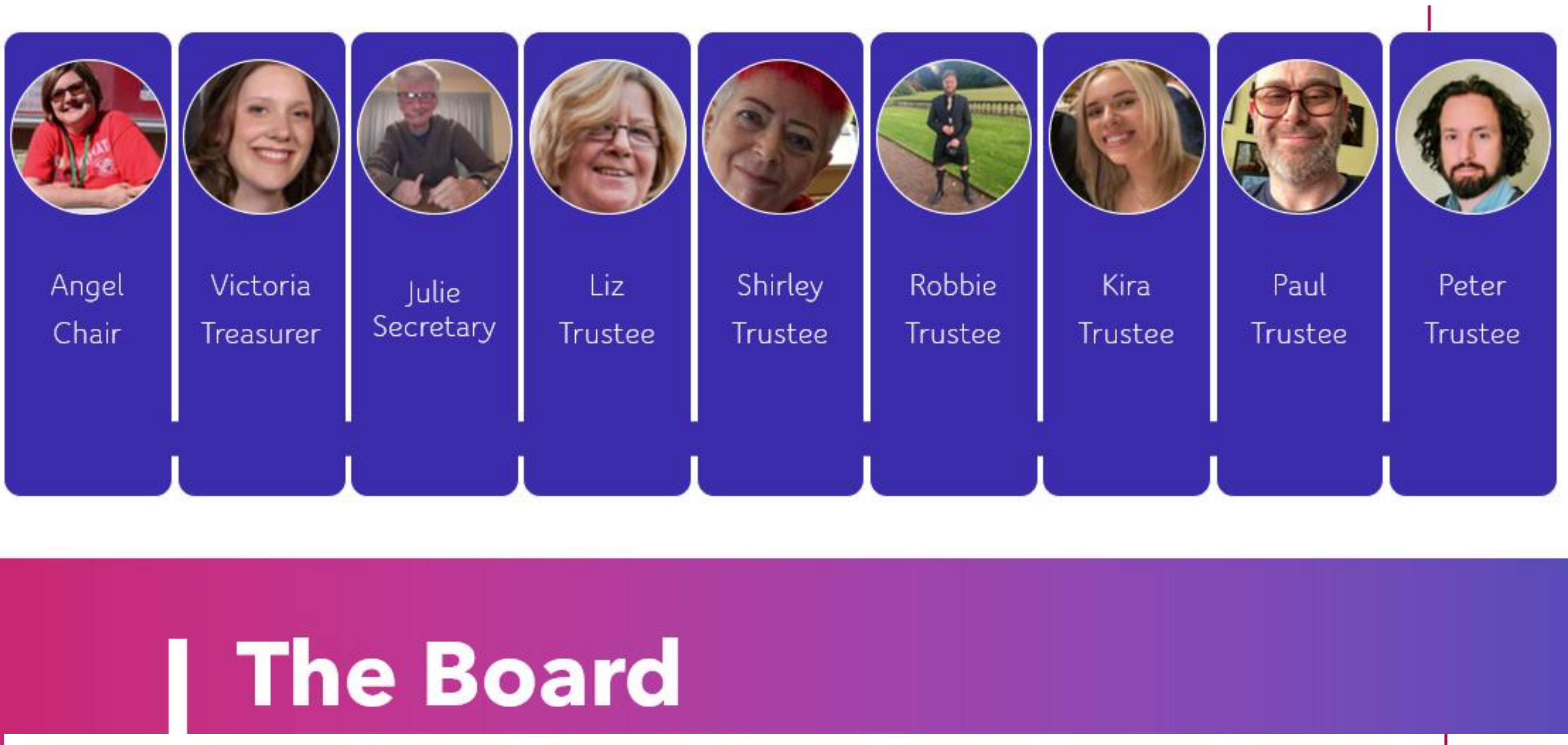
Funding is available for grassroots community groups based in the borough of Stockport delivering activities that contribute positively to wellbeing and improved health of local people .

Awards of up to £1,000 are available.

Souter CHARITABLE 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.



Trustee's Report - General Information

Registered Charity Number: 1188941
Flat 3, School Court, Meyer Street, Stockport, SK3 8JE

Trustees:

Our purpose

To relieve those effected by Poland Syndrome in particular but not exclusively by:

- Promoting improvements in care for people who are affected by Poland syndrome.
- Undertaking research into effects of Poland Syndrome and disseminating the useful results thereof
- Increasing awareness of Poland Syndrome amongst health professionals and the general public
- The provision of free advice and assistance to persons effected by Poland Syndrome and their families

Structure, Governance and Management

PIP-UK is a registered charity number 1188941, governed by the Charities Act 2006. The charity is a Charitable Incorporated Organisation registered on 7 April 2020 under the CIO Governing Document. New trustees are appointed by the serving trustees, considering the skills required by the board.

Activities

121 advice and support for families affected by Poland Syndrome. Advocacy services with health care professionals. Wellbeing services and family support services. Hosting events that bring the community together.

Trustee's Report - General Information

Registered Charity Number: 1188941
Flat 3, School Court, Meyer Street, Stockport, SK3 8JE

Public Benefit

The Trustees confirm that they referred to the Charity Commission's general guidance on public benefit when reviewing the Charity's aims and objectives for the year. Public benefit has been achieved as per the activities outlined in the 'Our Achievements' section of this report.

Financial Review

We have sufficient funds to support the planned projects and running costs and we will be working on diversifying our fundraising to support our growth and vision for the Poland Syndrome Community by increasing the community fundraising and reaching out to other grant providers.

Reserves Policy

The policy is designed to set out the process of determining the appropriate level of reserves that PIP-UK is required to hold in order to meet its requirements, while ensuring we are meeting the needs of our service users as best as possible.
This means ensuring we can meet our basic running costs, periods of funding and other uncertainty, while ensuring money is available to allow us to meet our charitable aims.