



# Vision and Mission

Embodying who we are and what we do

Presented by: Sam Fillingham

# Agenda



■ Overview

■ Meet the Team

■ Treasurers Report

■ Vision

■ Mission

■ Factors Shaping our Strategic Decisions

■ Key Goals

■ 2022 Roadmap

■ Save the Date

■ Call to Action





# The Team - Our Board of Trustees



**Angel Scott  
Bottoms**  
*Chair of Board*



**Liz Mckenna**  
*Secretary*



**Victoria Bedwell**  
*Treasurer*



**Robbie Woods**  
*Trustee*



**Shirley Proctor**  
*Trustee*



**Sue King**  
*Trustee*

## Our CEO



**Sam Fillingham**  
CEO & Project Lead

## Our Ambassadors



**Richard Stott**  
*Comedian, writer.*



**Becca Butcher**  
*Digital Creator*



**Kim Daybell**  
*Doctor and Paralympian*



**Lewis Hatchett**  
*Athlete Mindset & Mindfulness*





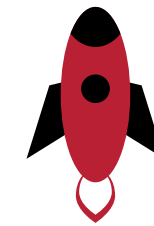
## Vision

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**

**MDT**

## 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 Poland Syndrome. Building awareness for Poland Syndrome and providing support to the community. Increase scientific activity.





# Factors Shaping Our Strategic Decisions



## Funding

We have funding for:

- The register through to June 22
- Basic keeping the lights on
- Completing our wellbeing pilots
- our event on 30th April.

We don't have funding for anything other projects



## Resources

We only have 1 staff member and have not built up our volunteer resources to a long term and sustainable level.



## Grant Landscape

A knock on affect of Covid-19 is that grant giving organisations are supporting more local initiatives as opposed to national charities like ours.



# Key short Term Goals

1

Secure funding to continue the momentum we have built in 2021 and fund our vital services.

2

Sign up 100 people to the register

3

Generate scientific activity

4

Scale and embed the wellbeing and support services





# Key short Term Goals

1

Start and pilot the women's circles as part of the wellbeing pilot programme\*

.

2

Complete the support packages as part of the wellbeing pilot programme\*

3

Update the website and SEO

.

4

Provide family support at the Poland Syndrome MDT Clinics



# Key Long Term Goals

1

Create a specialised poland syndrome clinic for adults

2

Produce medical papers that look into the affects on ageing with Poland Syndrome, Surgical outcomes

3

Define the path to treatment and diagnosis and have it adopted by NICE

4

Funded peer support and events where we can connect at regular intervals throughout the year

5

Expand the surveys in the register to include more medical information/surgeries etc





# Key Long Term Goals

(Not currently funded)

1

## International Medical Conference

People with lived experience at the heart of it so we can combine medical experience with lived experience

2

## US and AUS subsidiary charities

We have lots of members and supporters in these countries and they are both without a Poland Syndrome charity, given their populations it would be beneficial to re-create what we do there.

3

## Young leaders programme

4

## Dedicated family support resources

5

## Education & Awareness sessions for Maternity, Surgery & Genetics Professionals

# 2022 - OUR ROADMAP

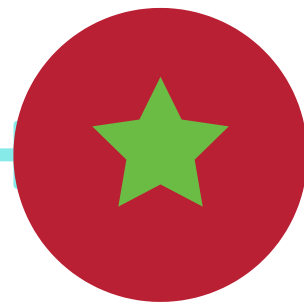
Whats happening in 2022?

**JANUARY**



- Launch the register and publish initial findings.
- Plan and launch women's circles
- Recruit the SAB
- Recruit organising committee for 30th April event

**FEBRUARY**



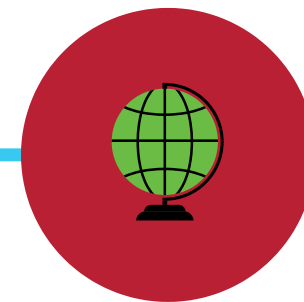
- Poland's MDT Clinic at Birmingham
- Rare Disease Day
- Find a Cure Showcase Virtual Booth

**MARCH**



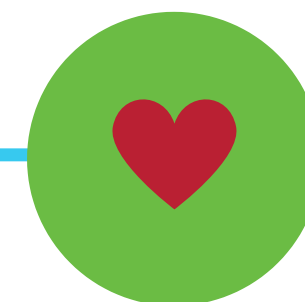
- PS Cuppa & Chat

**APRIL**



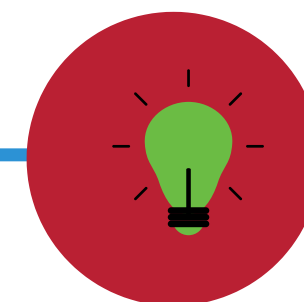
- Poland Syndrome Awareness Day Event - 30th
- Global Event
- Raffle

**MAY**



- PS Cuppa & Chat
- Poland's MDT Clinic at Birmingham

**JUNE**



- PS Cuppa and Chat



# 2022 - OUR ROADMAP

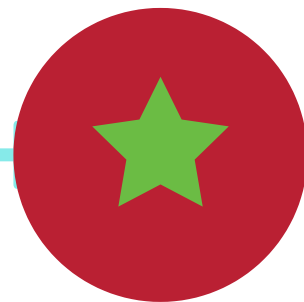
Whats happening in 2022?

JULY



- Tough Mudder - Dumfries
- PS Cuppa & Chat

AUGUST



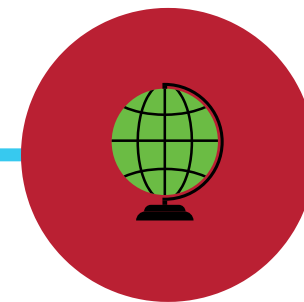
- PS Cuppa & Chat

SEPTEMBER



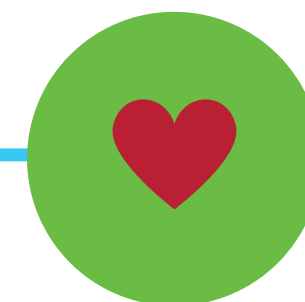
- PS Cuppa & Chat
- Poland's MDT Clinic - Birmingham

OCTOBER



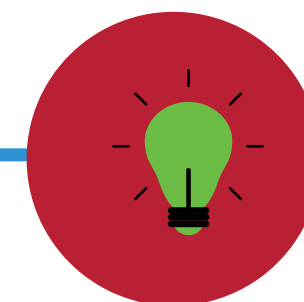
- AGM

NOVEMBER



- PS Cuppa and Chat

DECEMBER



- Poland's MDT Clinic Birmingham





Save  
the  
Date

## 30th April - Poland Syndrome Awareness Day

1. Please join us at the event in  
Stockport
2. Host an event at home or in  
your local community  
centre/park/school hall
3. Volunteer on the organising  
committee





# Save the Date

## 2nd July Tough Mudder - Dumfries

1. Robbie Woods and the ETAP team are entering to raise money for PIP-UK
2. All welcome to join that team
3. There is a mini tough mudder so its a fund day out for all ages as well as a good fundraiser

# Call to Action - We need you

## ORGANISING COMMITTEE FOR PS AWARENESS DAY

---

- If you like events and want to help organise, we need you!

e-mail

[pip.charity@gmail.com](mailto:pip.charity@gmail.com)

## FUNDRAISERS

---

- Please create or take part in a fundraising event to raise some much needed funds
- Cake Sale
- Book Sale
- Sponsored Walk
- Sponsored Bike Ride
- Bingo Event
- Pamper Evening
- Coffee Morning





# Thank you!

---

Feel free to approach us  
if you have any questions.