



Annual Report
For financial period 1st April 2020 to 30
March 2021

PIP-UK

Poland Syndrome Support &
Network

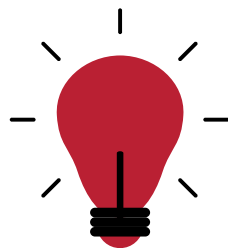


www.pip-uk.org Charity Registration Number :1188941



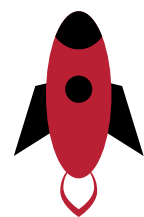
Vision

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.



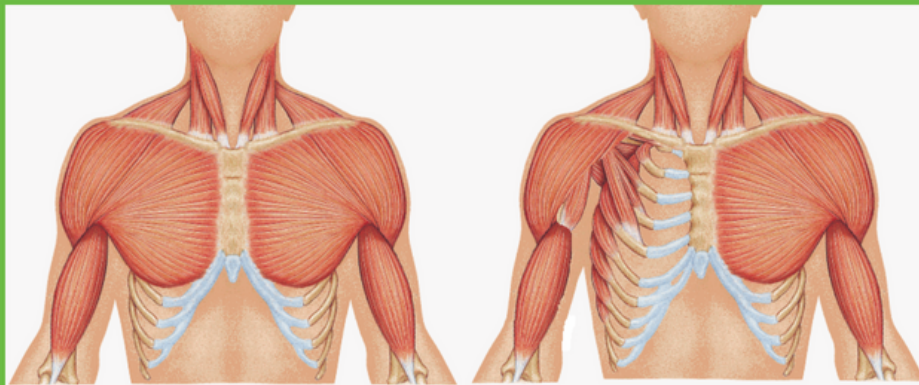
Goals

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

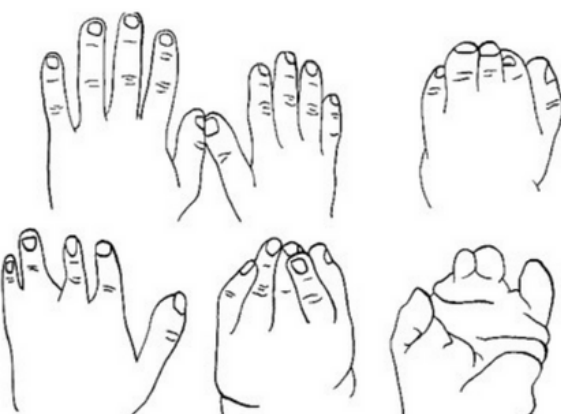
5-29% of people with Poland Syndrome have:
Aplasia/Hypoplasia of the sternum



66

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 and Our Achievements

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.



Clearly more needed to be done and our volunteers tirelessly gave their time, sharing experiences, giving peer support and raising funds. The community identified the following as key targets for the organisation:

1. Educate medical professions about Poland Syndrome to raise awareness and improve patient experience.
2. Provide a support network for people with Poland Syndrome and their friends and family members.
3. Signpost people to the right medical professionals who can give the right advice.

About PIP-UK and Our Achievements

We worked on meeting these key targets by:

- Hosting an annual Family Fun day/weekend to bring families together for peer support (a mix of in-person and online due to Covid-19).
- Recruiting ambassadors to raise the profile of Poland Syndrome, eg, Dr Kim Daybell, Paralympian and Jnr Doctor, Lewis Hatchett, cricketer, Richard Stott, comedian, Becca Butcher Content Creator & Mental Health Advocate, all with lived experience of PS.
- In March 21 we applied for funding to implement a Pilot Year of events and activities to support mental health and self-esteem amongst young people, women, and families of young children recently diagnosed with PS.
- Providing advocacy services for individuals and families and 121 support.
- Building relationships with surgeons, public health England and Rare Disease Network to increase awareness of Poland Syndrome amongst health care professionals.
- Beginning to work on our Poland Syndrome Community Register, the key building block to researching Poland Syndrome to improve treatment and diagnosis.



About PIP-UK and Our Achievements

The work we did and the community we supported blossomed to the extent we grew the membership by 44 people and appointed our first employee during this financial period.

We planned our first family weekend due to take place in August 2021. Designed to bring the community together for a weekend for the first time. Where they will enjoy peer support, make new friends, bond over outdoor activities and enjoy talks from prominent people with Poland Syndrome



Members of our community are not just volunteers and ambassadors, but active members of our Board of Trustees. The voice of the Poland Syndrome Community is at the heart of all we do.

Our Impact

In June 2020 we hosted an online family day which included medical talks, peer to peer support sessions, 121s with hand surgeon and psychological nurse practitioner and interactive games and magic show for children. 139 people participated on the day and with the recordings.

Here's what our community said about the day:

"What a fantastic day!! Thank you so much to all who helped make this day possible! It was very informative and VERY emotional! Hope to see you all next time,"

"Thank you to everyone involved in setting it up and meeting the participants was one of the most moving of personal experiences I've had."

"Yes thank you to all the volunteers and their hard work in getting this all together so that we could all get together. Even though it was 5.00 in the morning for me I enjoyed listening to all of your experiences, yes I did well up a few times . Keep up the good work PIP - UK."

"Thank you PIP -UK for arranging today... really enjoyed connecting with you all, such an amazing, kind and friendly poland community. Can't wait to see and chat to you all again soon."

"Thanks everyone for arranging a great day. We really found it useful & encouraging as parents to our little boy with Poland syndrome. It's great to know that there is a community of lovely people out there who understand your concerns and worries"



Our Impact

We reached over 30,000 people with our social media posts to raise awareness and help people with Poland Syndrome find us so we can provide them with support.



PIP - UK Poland Syndrome Support

3 September 2020 · 🌐

...

We're asking you to share this post today. For two reasons:

1. Raising awareness of Poland Syndrome and educating people is a huge part of what we do
2. Not everyone with PS is diagnosed at birth. Not everyone is born with a hand difference. We have read stories of worried parents rushing young children to hospital with what they describe as a "sunken" chest, when they suddenly notice something isn't right. Can you imagine how alarming and scary that must be? And it's not always babies some children can be 5 or 7 years old before it's noticed.

So please help us out. Share this post. Let's raise awareness. You never know who this might help out there.

Thank you





PIP Parents information Portal - Operating as PIP-UK Poland Syndrome Support and Network

Trustee's Report - General Information

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

Trustees:

Angel Scott-Bottoms (Chair)

Liz Mckenna (Secretary)

Victoria Bedwell (Trustee Dec 20 & Treasurer from 10 May 21)

Shirley Proctor (Trustee)

Robbie Woods (Trustee from Dec 20)

Sue King (Trustee)

Louise Marshall (Treasurer Dec 20-April 21)

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.

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.



PIP Parents information Portal - Operating as PIP-UK Poland Syndrome Support and Network

Trustee's Report - General Information

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

Reserves Policy

This 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.

Using guidance from the Charity Commission, we have identified that our reserves policy is split between the below items, to ensure confidence in our going concern.

Running Costs

Taking into account our number of paid staff, and notice periods (where applicable), our reserves should cover at a minimum the notice period of these paid staff members, including salary, pensions, and associated tax.

Where other running costs become applicable (for example, rent), this will be considered.

Variances in Funding Streams and Restricted Funds

PIP-UK has high reliance on individual fundraisers and donations, which by nature is a variable funding source. While PIP-UK does gain support via grants from individual organisations of generally between 0 and 10,000 pounds, these are not repeating grants.

In general, the expectation would be for a peak in funding streams around 'PS Awareness Day', and potentially events such as Christmas, with troughs in funding streams around these dates.

To ensure going concern, PIP-UK will consider the variability of the funding streams in place, and identify and acknowledge any income that should be placed to a Restricted Fund. There is therefore an expectation in our Reserves Policy that PIP-UK will hold higher reserves than our identified range for part of the year, which will be retained to 'flatten' the expected trough in funding at other parts of the year.

Based on the variability of funding streams, and on the basis that PIP-UK is a relatively new charity, we have also identified mitigating processes in the event our expected reserves level cannot be maintained. On discussion with our key third party supplier of the Registry, we have identified alternative payment processes in an emergency event; we have also identified minimum contractual hours that would be possible to maintain the charity's existence in such an event.



PIP Parents information Portal - Operating as PIP-UK Poland Syndrome Support and Network

Trustee's Report - General Information

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

Reserves Policy

We are also working towards diversifying our income streams as part of the awareness programme, with the aim to bolster basic levels of funding throughout the year.

Lower and Upper Range of Reserves

Based on the above, we will have a lower and upper range of reserves that will be reviewed on an at least annual basis to ensure this remains appropriate to our running costs and charitable aims.

This policy has been reviewed in July 2022, at which point the expected level of reserves held is agreed as:

4,000 - 5,000 GBP.

This is based on one paid employee with one month notice period.

We note currently the payment for the Registry is considered a Restricted Fund of 10,000 GBP; as such 10,000 GBP of income has been withheld from our reserves for this payment.

Total funds held at Annual Return date: 18991.49

Amount considered restricted funds: 10000 [required for registry; expected to be paid in Aug-Sept]

Unrestricted funds at Annual Return date: 8991.49

Difference between reserves held and expectation per Reserves Policy = +3991.49.
See explanation in 'Amount of reserves held' below for an explanation of the difference.

Amount of reserves held

Expected level of reserves are approximately 2 months of required spend = 4,000 to 5,000 GBP.

Amount of reserves held at date of filing = 8991.49 [excluding amount retained as a restricted fund for the registry].

Excessive reserves held at point in time due to expected increase in funding from recent PS awareness day activities and receipt of grants.

Other

The accounting period was changed in January 2022, we were not aware of the implications to our annual reporting year for the charities commission as this is our first year of submission. Please accept our apologies for this omission and all trustees are now aware of the rules regarding accounting years and reporting.

PIP Parents Information Portal

Report of the Trustees and Unaudited Financial Statements

For the period ended 31 March 2021

Draft

PIP Parents Information Portal
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For the period ended 31 March 2021

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PIP Parents Information Portal
Report of the Trustees
For the period ended 31 March 2021

The Trustees have pleasure in presenting their report and the financial statements for the charity for the period ended 31 March 2021. The Trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and the Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Objectives and aims

The trustees have considered the Charity Commission's guidance on public benefit, including the guidance 'public benefit: running a charity (PB2)'.

REFERENCE AND ADMINISTRATIVE INFORMATION

Name of Charity	PIP Parents Information Portal
Charity registration number	1188941
Principal address	3 School Court Meyer Street Stockport Cheshire SK3 8JE

Trustees

The trustees and officers serving during the year and since the year end were as follows:

Ms Angel Scott-Bottoms
(Appointed: 07 April 2020)
Ms Victoria Bedwell
(Appointed: 19 December 2020)
Mr Robbie Woods
(Appointed: 19 December 2020)
Ms Elizabeth McKenna
(Appointed: 07 April 2020)
Ms Shirley Blair-Proctor
(Appointed: 07 April 2020)
Ms Sue Kindred
(Appointed: 07 April 2020)

Independent examiners	ABS Accountancy Ltd 10 Fairfield Road Buxton Derbyshire SK17 7DW
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Bankers	The Co-Operative Bank
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Approved by the Board of Trustees and signed on its behalf by

PIP Parents Information Portal
Independent Examiners Report to the Trustees
For the period ended 31 March 2021

I report on the accounts of the charity for the period ended 31 March 2021, which comprise the Statement of Financial Activities, the Statement of Financial Position and the related notes.

Respective responsibilities of trustees and examiner

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) and that an independent examination is required.

It is my responsibility to:

- examine the accounts under section 145 of the 2011 Act;
- to follow the procedures laid down in the General Directions given by the Charity Commission (under section 145(5)(b) of the 2011 Act); and
- to state whether particular matters have come to my attention.

Basis of independent examiner's report

My examination was carried out in accordance with the General Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

Independent examiner's statement

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

(1) which gives me reasonable cause to believe that, in any material respect, the requirements:

- to keep accounting records in accordance with 130 of the 2011 Act; and
- to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 2011 Act

have not been met, or

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

.....
ABS Accountancy Ltd
10 Fairfield Road
Buxton
Derbyshire
SK17 7DW

PIP Parents Information Portal
Statement of Financial Activities
For the period ended 31 March 2021

	Notes	Unrestricted funds £
Income and endowments from:		
Donations and legacies	2	22,744
Other trading activities	3	977
Investments	4	11
Total		23,732
Expenditure on:		
Raising funds	5/6	(1,900)
Charitable activities	7/8	(3,298)
Total		(5,198)
Net income		18,534
Total funds carried forward		18,534

Draft

PIP Parents Information Portal
Statement of Financial Position
As at 31 March 2021

	Notes	2021 £
Current assets		
Cash at bank and in hand		21,344
		21,344
Creditors: amounts falling due within one year	12	(275)
Net current assets		21,069
Total assets less current liabilities		21,069
Creditors: amounts falling due after more than one year	13	(2,535)
Net assets		18,534
The funds of the charity		
Unrestricted income funds	14	18,534
Total funds		18,534

The financial statements were approved and authorised for issue by the Board and signed on its behalf by:

Draft

PIP Parents Information Portal
Notes to the Financial Statements
For the period ended 31 March 2021

1. Accounting Policies

Basis of accounting

The financial statements have been prepared under the historical cost convention, except for investments which are included at market value and the revaluation of certain fixed assets and in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102), and the Charities Act 2011.

PIP Parents Information Portal meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

Going concern

2. Income from donations and legacies

Unrestricted funds

Donations received

Grants received

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2021

£

2,744

20,000

22,744

3. Income earned from other activities

Unrestricted funds

Fund raising events

2021

£

977

977

4. Investment income

Unrestricted funds

Bank interest receivable

2021

£

11

11

PIP Parents Information Portal
Notes to the Financial Statements Continued
For the period ended 31 March 2021

5. Expenditure on generating donations and legacies

	2021 £
Unrestricted funds	
Donations	510
	<u>510</u>

6. Expenditure on other trading activities

	2021 £
Unrestricted funds	
Fund raising events	1,390
	<u>1,390</u>

7. Costs of charitable activities by fund type

	2021 £
Unrestricted funds	
Support costs	3,298

8. Costs of charitable activities by activity type

	2021 £
Support costs	
Activity 1	3,298

9. Analysis of support costs

	2021 £
Activity 1	
Management	1
IT	351
Governance costs	2,946
	<u>3,298</u>

PIP Parents Information Portal
Notes to the Financial Statements Continued
For the period ended 31 March 2021

10. Net income/(expenditure) for the period

This is stated after charging/(crediting):

	2021
	£
Accountancy fees	275
	<u>275</u>

11. Staff costs and emoluments

Total staff costs for the period ended 31 March 2021 were:

	2021
	£
Salaries and wages	1
	<u>1</u>

12. Creditors: amounts falling due within one year

	2021
	£
Accruals and deferred income	275
	<u>275</u>

13. Creditors: amounts falling due after more than one year

	2021
	£
Other creditors	2,535
	<u>2,535</u>

14. Movement in funds

Unrestricted Funds

	Incoming resources £	Outgoing resources £	Balance at 31/03/2021 £
<i>General</i>			
General	23,732	(5,198)	18,534
	<u>23,732</u>	<u>(5,198)</u>	<u>18,534</u>

PIP Parents Information Portal
Notes to the Financial Statements Continued
For the period ended 31 March 2021

15. Analysis of net assets between funds

	Net current assets / (liabilities) £	Creditors > one year £	Net Assets £
Unrestricted funds			
<i>General</i>			
General	21,069	(2,535)	18,534
	21,069	(2,535)	18,534

Draft

PIP Parents Information Portal
Detailed Statement of Financial Activities
For the period ended 31 March 2021

	2021 £
INCOME AND ENDOWMENT	
Donations and legacies	
Donations	2,744
Grants receivable	20,000
	<hr/> 22,744
Other trading activities	
Fund raising events	977
	<hr/> 977
Investments	
Bank interest receivable	11
	<hr/> 11
Total incoming resources	<hr/> 23,732
EXPENDITURE	
Raising donations and legacies	
Donations	(510)
	<hr/> (510)
Other trading activities	
Fund raising events costs	(1,390)
	<hr/> (1,390)
SUPPORT COSTS	
Management	
Management	(1)
	<hr/> (1)
IT	
IT	(351)
	<hr/> (351)
Governance costs	
Governance costs	(2,946)
	<hr/> (2,946)
Total resources expended	<hr/> (5,198)
Net Income	<hr/> <hr/> 18,534

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