# Annual Impact Report

Action for XP
Support. Educate. Connect.

1st April 2022 - 31st March 2023

**Action for XP (SCIO)** Charity no: SCO45465 www.actionforxp.org

# Support
# Educate
# Connect

## contact us

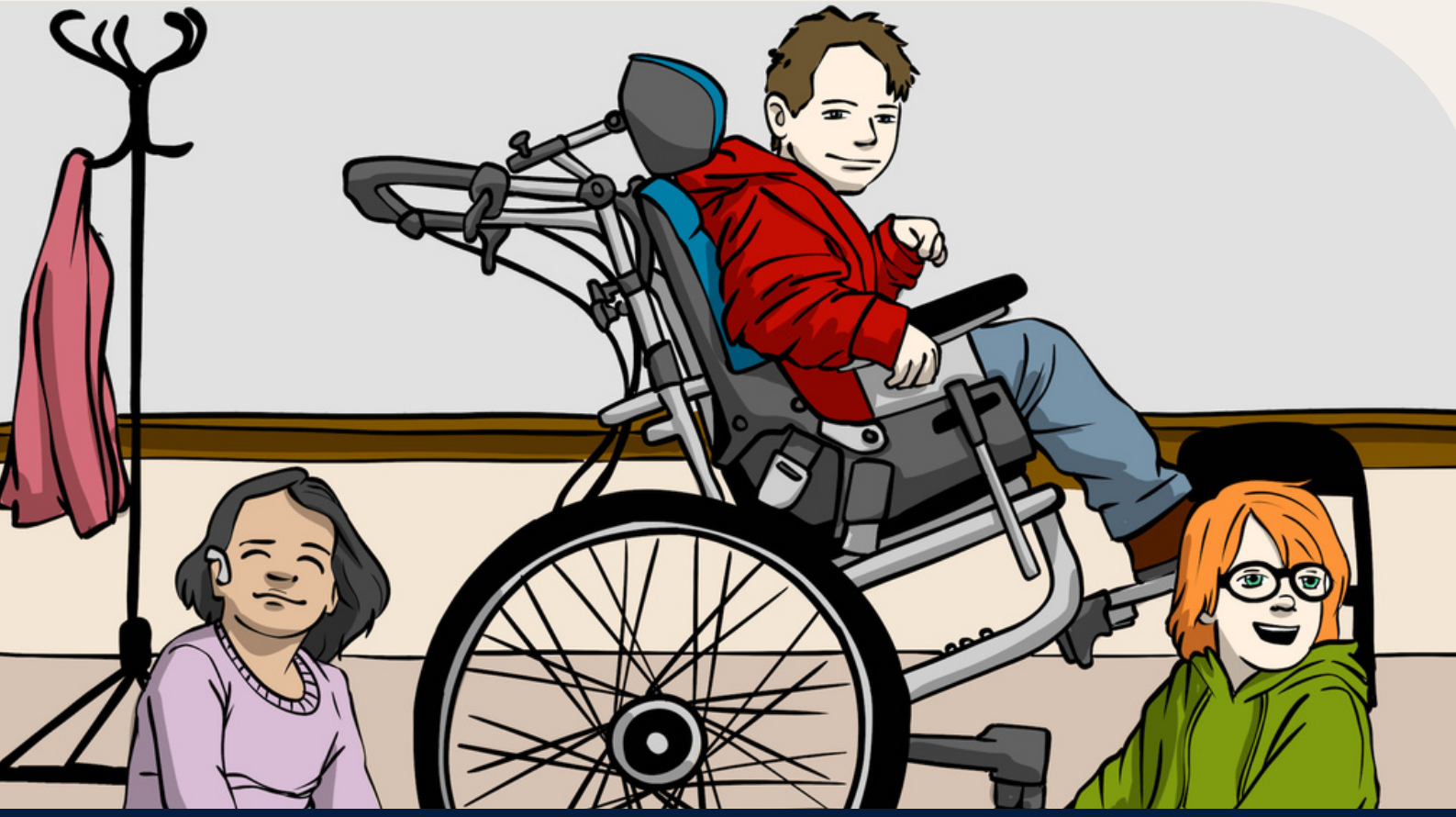
**Action for XP (SCIO)**
Scottish Charitable Incorporated Organisation: **SCO45465**

**Registered address:**
Westfield, Cushnie, Alford,
Aberdeenshire, AB33 8LP

**www.actionforxp.org**

**support.actionforxp.org**

**@ActionforXP**



# Structure, governance, management, *mission*

Teddington Trust was founded by Rebecca and Wilbur Stewart, and Nicola Miller in 2012 and was recognised as a Scottish Registered SCIO on the 6th March 2015. On the 1st July 2022 Teddington Trust successfully rebranded as Action for XP, better reflecting the demographic of our service users and our future direction. Our focus remains to **support, educate and connect** , in pursuit of improved lives for our beneficiaries.

- To provide practical and emotional support to individuals and families regardless of age and stage of life
- To reach underserved regions internationally by collaboration and knowledge sharing
- To further scientific understanding of XP through research and dissemination of research
- To provide education and awareness within the XP community and externally
- To promote inclusivity, diversity and equality operationally and across our activities

## Trustee recruitment, and resignations

The Action for XP board formed in July 2022, comprised existing members of Teddington Trust, who remained unchanged from previous years, with the recruitment of Annette (Nettie) Dearmun, Ellie McGowan and Flora Milligan who joined us from the XP Support Group, (XPSG closed its doors in 2022 after 25 years of service). Due to a change in personal circumstances Flora Milligan resigned from her role as Fundraising Trustee on the 23rd December 2022.

## Volunteers

In addition to our board we are supported on a regular basis by the following volunteers:

Eunice Gelati (resource dispatch)
Emily Ballinger (social media)
Izzy Owens (social media)
Emily Robertshaw (research)
Farah Akhtar (patient support)

## *Board of Trustees*

| | | |
|---|---|---|
| **Dr. Richard Barlow** | **Chair of the Board** | **Trustee, XP patient, Dermatology Registra** |
| Rebecca Stewart | Treasurer | Trustee, XP family |
| Nicola Miller | Secretary | Trustee, XP family |
| Dr. Nettie Dearmun | Clinical liaison | Trustee |
| Ellie McGowan | Safeguarding officer | Trustee |
| Wilbur Stewart | | Trustee, XP family |
| John Roberts | | Trustee |

Doctor Richard Barlow,
Chair of Trustees, Action for XP

# Letter from our *Chair*

The past 12 months have flown by; July 2023 marks one year of Action for XP. Nicola, Nettie, Rebecca and regular volunteer Eunice, continue to make great impact through direct patient support both nationally and internationally. The XP clinic in London continue to deliver excellent care to our patients and their families affected by XP, including myself. We look forward to continuing and building on this working relationship in the years to come.

As our community grows, we have had to enforce some changes to our services to ensure sustainability of the charity. We thank our community for their patience and understanding in these matters which allows us to deliver the core services to greater numbers of people and ensure long-term continuation of Action for XP.

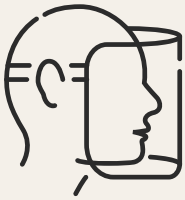
This year has also seen the launch of a wonderful comic focusing on the neurological aspects of XP and the transitional phase of childhood and beyond. We thank the team behind this based in Dundee and beyond.

Lastly, a heartfelt thank you to all the inspirational individuals who continue to fundraise and raise the profile of XP within the UK and abroad. We are still not out of the post-pandemic woods which makes everything considerably more challenging and we very much recognise the great efforts of those people who continue to persevere and set leading examples for the rest of us.

**richard.actionforxp.org**

# The year *in review*

**The following resources were dispatched directly to patients across the UK and internationally by our volunteer team**



**74**

UV protective face visors and legionnaires hats

**30**

Little Ted bears and story book packs sent to new forever homes

**72**

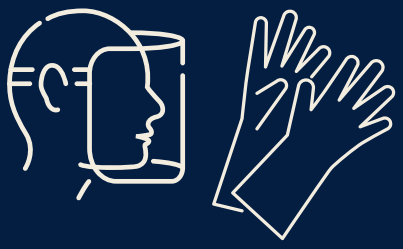
Pairs of UV protective gloves

**39**

Rolls of UV protective film

## *Patient resources in clinic*

The following resources were provided to the NHS National XP Service, at the Rare Disease Centre, St Thomas' Hospital, London, to be disseminated to newly diagnosed children and adults attending the clinic.



**8**

Patient packs; containing UV protective face visors/hats and gloves to be given to newly diagnosed adults and children in clinic

**5**

Little Ted bears and story book packs for newly diagnosed children

"In 2022-2023 we shipped vital life-saving UV protective patient resources to 14 different countries across the globe."

14

Patients supported in **14 difference countries**, including:

USA, Australia, Romania Turkey, Pakistan, Brazil Maldives, Indonesia, the Arab Emirates and Nepal

## Patient support

2 Awards of home or car protection grants

45 Funded trips to attend medical appointments at specialist NHS XP Service

7 Online virtual community meet ups hosted

5 DLA/PIP or Blue Badge applications supported

1

Family supported via our pilot mental health support programme RARE Minds; providing 12 fully-funded counselling sessions

100s and 100s of emails, telephone calls, 1-2-1 Zooms chats, Whats App and voice messages responded to!

"In response to feedback from our community we now host twice monthly virtual meet-ups via Zoom. A morning and evening session each month allows increased accessibility for those who work, have young children or are joining us from different timezones. "

**FIRST Thursday at 11.00 (BST)**
**LAST Wednesday at 19.00 (BST)**

Details of our virtual meet-ups are shared on Facebook and in our regular e-newsletter

# Education and awareness

**We provide relief to patients and families affected by xeroderma pigmentosum by way of funding; health, educational and recreational projects.**

**6** Conferences, events and talks attended

**5** External media opportunities

**217** views of our online new teen educational comic (phase 1)

## In the media

- **https://www.healthawareness.co.uk/dermatology/leave-no-one-behind-in-providing-access-for-the-entire-xp-community/**
- **https://www.m4rd.org/podcast/**
- **https://bit.ly/XP-MoreThanSkinDeep**
- **Profcast webinar – The Revolution Rolls #05 The rare revolution rolls - Der Profcast - Seltene Erkrankungen und ihre Therapien | Podcast on Spotify**


Eddison Miller (12) won the Try Angle Community Action Award for his district, recognising his work in raising awareness for being a child living with XP

# The advancement of education

## Conferences and training

With COVID-19 restrictions now lifted we have been able to increase our activity of in-person events. This has included attending:

- Rare Fest 2023
- BAD conference
- NHS Disease awareness training days
- Rare Disease Day at St Thomas' Hospital
- In-school talks

## Raising awareness

We continue to work hard to raise the profile of XP through in-school talks, articles, radio and podcasts and through our own social media campaigns.

This year we were thrilled to take part for the second year in the Guardian Skin Health campaign, taking about the importance of working for improved equity for all living with XP.

## Memberships and alliances

We continue to build our network of collaborators and partners through membership and alliances with the following:

- Global Genes Alliance
- Global Skin
- British Association of Dermatologists
- Genetic Alliance
- RARE Revolution Charity Partner

"We simply couldn't do what we do without the support from our volunteer Eunice (my mum), who makes up every package we ship ."

Nicola Miller, Patient Support

# Patient *Liaison*

This year has seen a steep increase in demand for support and resources across the UK and internationally. In the last year we have dispatched patient resource packs to 14 different countries, each with their own challenges for navigating in terms of shipping logistics.

We are able to serve our international community due to our ongoing and highly valued partnership with the courier DHL and the ongoing support of our volunteer Eunice who holds all our stock, and makes up and distributes these packs from her own home.

As an ongoing legacy from the COVID-19 pandemic we have found great value in continuing to host our monthly online virtual community Zoom sessions, and have now increased this to two sessions per month.

The escalating costs of travel have seen our support for attendance of medical appointments challenged and render this no longer sustainable. We have been greatly appreciative of the support from both our community and clinical staff in embracing our reformed grant reimbursement scheme.

## Supporting you

With our new website we have made it easier than ever to access support:

**support.actionforxp.org**

**admin.actionforxp.org**

Patient support request:
www.actionforxp.org/patient-support-enquiry.html
Action advice hub:
https://www.actionforxp.org/action-advice-hub.html
Schools hub:
https://www.actionforxp.org/schools-hub.html

Project breakaway (recreation and leisure):
https://www.actionforxp.org/project-breakaway.html
Travel grant application:
http://www.actionforxp.org/uploads/1/1/0/9/11094435/medical_travel_financial_assistance_advice_final.pdf

# Recreational respite

**Improving quality of life through recreational opportunities.**

## 50 for FREE

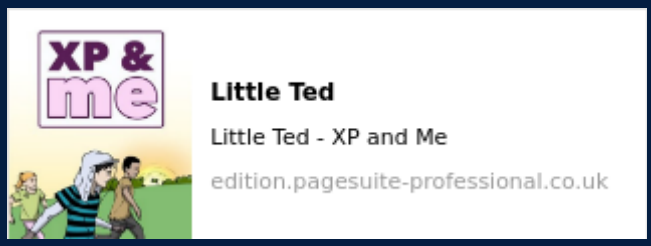
Action for XP were fortunate to be awarded a free weekend trip for one of our beneficiaries, through the Landmark Trust, 50 for FREE programme. Following a successful ballot across our beneficiaries, Louis and his family enjoyed a lovely weekend at Wilmington Priory. Read about their adventure here: **www.actionforxp.org/news/a-landmark-adventure**

Guidance on UV safe sites secured by us are available at: **www.actionforxp.org/project-breakaway.html**

Louis and his family enjoyed a glorious family weekend thanks to the Landmark Trust 50 for FREE award to Action for XP

# Promotion of equality and diversity

In February 2023 we launched phase 1 of our teen comic project: XP & Me. This addresses themes identified by our youth community as important: XP Information, What XP is and what it isn't and Neurology & XP.




Our young people worked closely with the artists on the project to ensure that the stories, characters, words and artwork reflected them, and the diversity of the global XP community.

**www.actionforxp.org/news/co-creating-educational-resources-to-empower-young-people**
**https://bit.ly/XP-And-Me**

# Research and scientific advancment

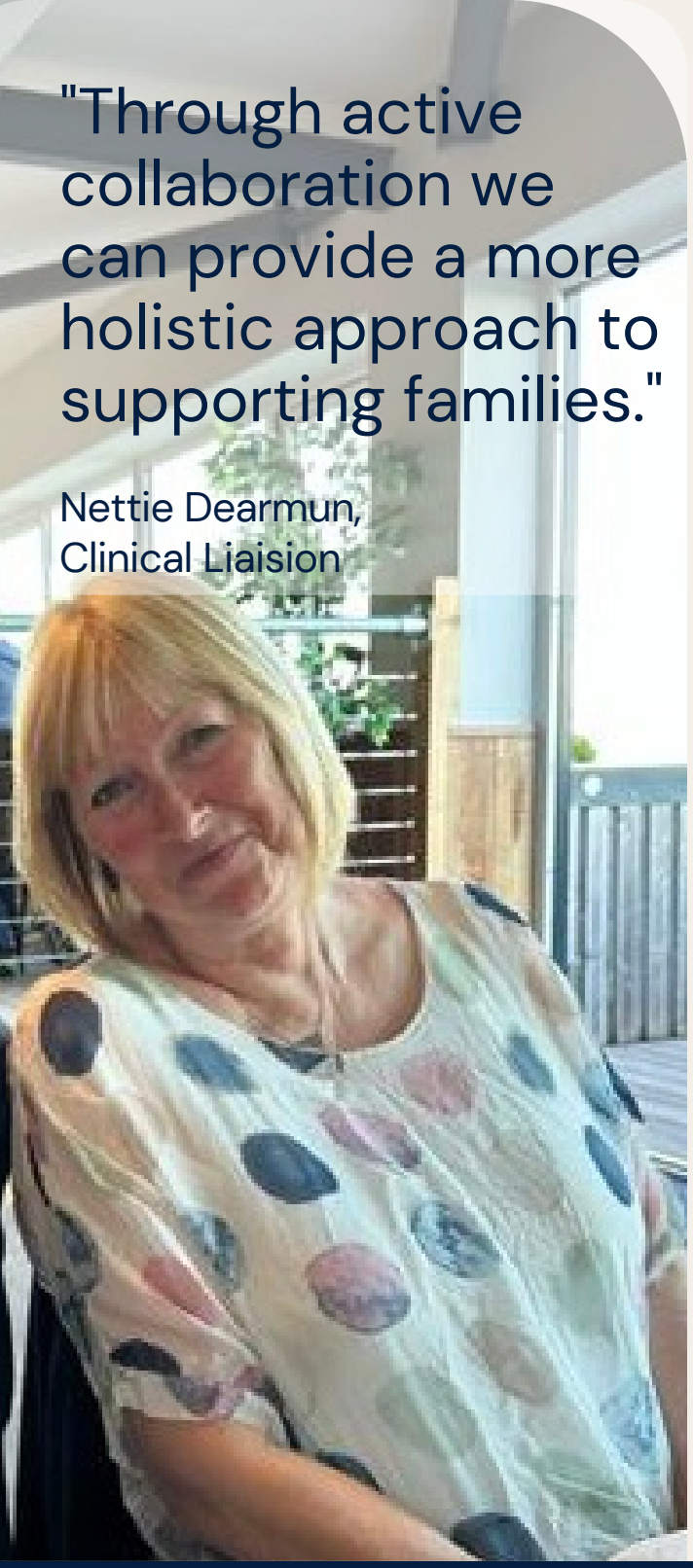
We were thrilled to feature in the Spring edition of RARE Revolution Magazine, in the RARE Neurology edition, with our article **More than skin deep.**

We talked about our hopes for research into future treatments for the neurological manifestations of XP and shared the impact of living with such impairments.

**Read in full here: https://bit.ly/XP-MoreThanSkinDeep**

"Through active collaboration we can provide a more holistic approach to supporting families."

Nettie Dearmun,
Clinical Liaision



# Clinical Liaison

A primary purpose of my role is to provide a link between the Action for XP Board and the clinical team, thereby maximising the contribution of the board, enhancing the experience of those attending clinic and encouraging partnership and harmonious working between the Board and the clinicians.

This year there have been several opportunities to come together to solve problems; influence policy and practice. These included a joint response to the discontinuation of sunscreen prescriptions; informing the development of the new travel grant and implementation of psychological support to augment that offered by the clinical team.

Collection of feedback from clinic attendees, analysis of the themes and discussion with the clinical team is vital in order to inform any necessary changes across our collective service delivery. We are currently exploring electronic systems that will streamline the distribution and analysis process while making it easier for individuals to feed back their insights in an anonymous and user-friendly way. We look forward to sharing this in due course.

Although there are physical resources available in clinic, many attendees find it reassuring to meet someone else who has firsthand experience of living with the condition. We would like to recruit a team of volunteers, willing to attend the clinic to explain the Action for XP organisation and signpost what it can offer. No qualifications necessary, just a desire to support the XP community. Interested parties can contact nettie@actionforxp.org to learn more.

# Building partnerships

The NHS funded Xeroderma Pigmentosum (XP) Multi-Disciplinary clinic was established in April 2010 to provide expert clinical care for patients thought to have or diagnosed with XP.

Action for XP is an integral part of the service giving feedback on the patient experience of the service as well as providing on-the-ground peer support and financial assistance for patients to attend the clinic.

For further information please visit

https://www.guysandstthomas.nhs.uk/our-services/xeroderma-pigmentosum-xp

**nettie.actionforxp.org**

"It is a challenging time to run a charity and the fundraising landscape looks vastly different post the COVID pandemic."

Rebecca Stewart, Treasurer

# Finances *in review*

This year we have greatly benefited from the funds which came to us from the XP Support Group, a total of £55,511.64. This has been a life line as community fundraising remains stubbornly low post pandemic. This worrying trend is being seen right across the third sector and for a second year we've been unsuccessful in filling our charity sporting places. However, funds did increase from 21/22 with both donations from sponsored events and private donations increasing by around 50%. We also received a grant of £4,324.43 from Horizon Therapeutics for international outreach. This will fund the translation of the Little Ted books into Portuguese to support a large patient cohort in Latin America and providing accessible education in region.

£2,527.50 in costs were incurred for our Little Ted book and bear project with both stocks needing replenishment this year. Continued investment in the rebrand with new patient and public website, leaflets, display materials and branded t-shirts for charity events resulted in costs of £5,300. Our patient liaison service again saw the largest percentage cost increase with demand more than doubling that of 21/22, to £6,740.61. The costs of travel and accommodation when attending clinic at St Thomas & Guys, have increased exponentially. As a result, it was necessary to take the difficult decision to reform the process and introduce the Clinic Travel Grant scheme. This has enabled us to redistribute finite funds, to benefit an increasing number. Thank you for your understanding and support.

We close the accounts with a year end surplus of £42,319.50.

**rebecca.actionforxp.org**

## Funding summary

**£6,323**
Donations, fundraising

**£4,324**
Grant funding

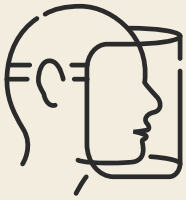
**£23,839**
Expenditure

**£61,419**
Closing balance

# Projects costs *at a glance*

Little Ted book and bear educational resource project

**£2,528**



Patient protection packs (hats/visor, gloves, film)

**£6,741**

Travel cost for patient attendance of National XP Service (45 visits)

**£13,605**

Home and car protection grants (Dermaguard film)

**£1,985**

Teen comic educational resource project

**£1,480**
(phase 1)

# Leave a gift *in your will*

## Could you leave a gift in your will ?

"Leaving a gift in your will helps secure our services long into the future, creating a lasting legacy for the global xeroderma pigmentosum community."

**IF YOU WOULD LIKE TO SPEAK TO SOMEONE ABOUT LEAVING A GIFT IN YOUR WILL OR TO MAKE A REGULAR DONATION NOW PLEASE GET IN TOUCH:**

rebecca@actionforxp.org

# The *future...*

As we look to the year ahead there is so much more we want to achieve.

With an ever-increasing workload putting considerable pressure on our volunteers we recognise the need to address this. Our hope is to be able to bring some part-time staff into the organisation in the year ahead, which, will help alleviate these pressures and allow us to delivering more for our families.

**Our priorities for 2023-2024 will include the following:**

- Recruit a new fundraising officer to help us take a more planned and strategic approach to raising funds and securing our financial sustainability
- Recruit support on day-to-day operations to alleviate pressure on existing volunteers
- Develop phase 2 of the teen comic project and expand youth engagement
- Continue to build on our monthly virtual get togethers
- Continue engagement with the community to develop a calendar of important in-person events to suit the needs of our diverse community
- Build on the success of the pilot project and secure funding to roll out our Rare Minds counselling programme fully

" My brother got diagnosed a year ago and I've seen how hard it has been for him **before** he got the support he needed with Action for XP... Action for XP provided him with very much needed and important support and protective clothing for him to be able to go outside and even funded special window film so he was safe inside the home.

I can't thank you enough for all the help he and my family have received throughout this whole process. We couldn't of done it without the support or service from this amazing charity."

**Sibling**

" The sessions were very important. I didn't realise how much I needed to talk to someone. It really helped because the person I spoke to was not connected to the team from the hospital. I am sure this will help 100% in the future with others. It is a service which I feel is much needed. Thank you so so much for your help."

**Parent,**
**counselling pilot recipient**

# We'd like to thank all our donors for their *generous support*

## Acknowledgements

Special thanks to regular fundraisers, **The Bishop Family**, and **Steve and Sandra Webb** who took part in fundraising activities for us this year, and to the following **regular donors** who help support our work year round:

**Alexander Burnett**
**Alan Lehmann**
**Alan Rymer**
**John Wasuluk**
**Sandra and Steve Webb**