



**Support. Educate. Connect.**

# **Recruitment Information Pack**

**Fundraising and Events Officer  
(part-time)**

Action for XP  
Charity ref: SC045465  
[www.actionforxp.org](http://www.actionforxp.org)

## Our Story

Founded in 2012, Action for XP (previously known as Teddington Trust), started as a family run organisation following the diagnosis of a family member with the ultra-rare condition; **xeroderma pigmentosum (XP)**. Since then we have continued to expand our reach and services, provide support and education to the global XP community.

2022 marked an important milestone: whereby we underwent a big rebrand and came together with another UK XP charity, (previously XP Support Group). This allowed us to combine resources and expertise from both organisations to expand our board, capacity and reach.

As part of our long term strategy for succession planning we would like to recruit talented individuals to join our team. Helping us continue to make a difference long into the future.

## What is XP?

XP is an ultra rare condition where individuals lack a fully functioning DNA repair mechanism.

This makes their skin more susceptible to damage from ultraviolet (UV) light, primarily from the sun and certain types of artificial lighting. This results in patients being 10,000 times more at risk of skin cancer, meaning that photo protection is vital to ensure their skin stays protected.

At least 30% of people with XP have a neurological impairment including hearing, sight and or central nervous system problems.

- XP is an autosomal recessive genetic condition (this means it has no bearing on whether you have X or Y chromosomes)
- Both parents need at least one copy of the affected (carrier) gene; resulting in a 25% chance of a child having the condition
- There are 7 types (complementation groups) of XP; groups A-G plus a further XP-variant, XP-V
- There are less than 200 people with XP in the UK and similarly low numbers all around the world
- XP can be life-limiting and currently there is no cure. Treatment is supportive making support groups a vital resource.

## Our Team

Action for XP is governed by a **Board of Trustees** who bring together a wealth of lived experience. Our team has a variety of professional skills essential in delivering innovative and vital community support, education and research activity.

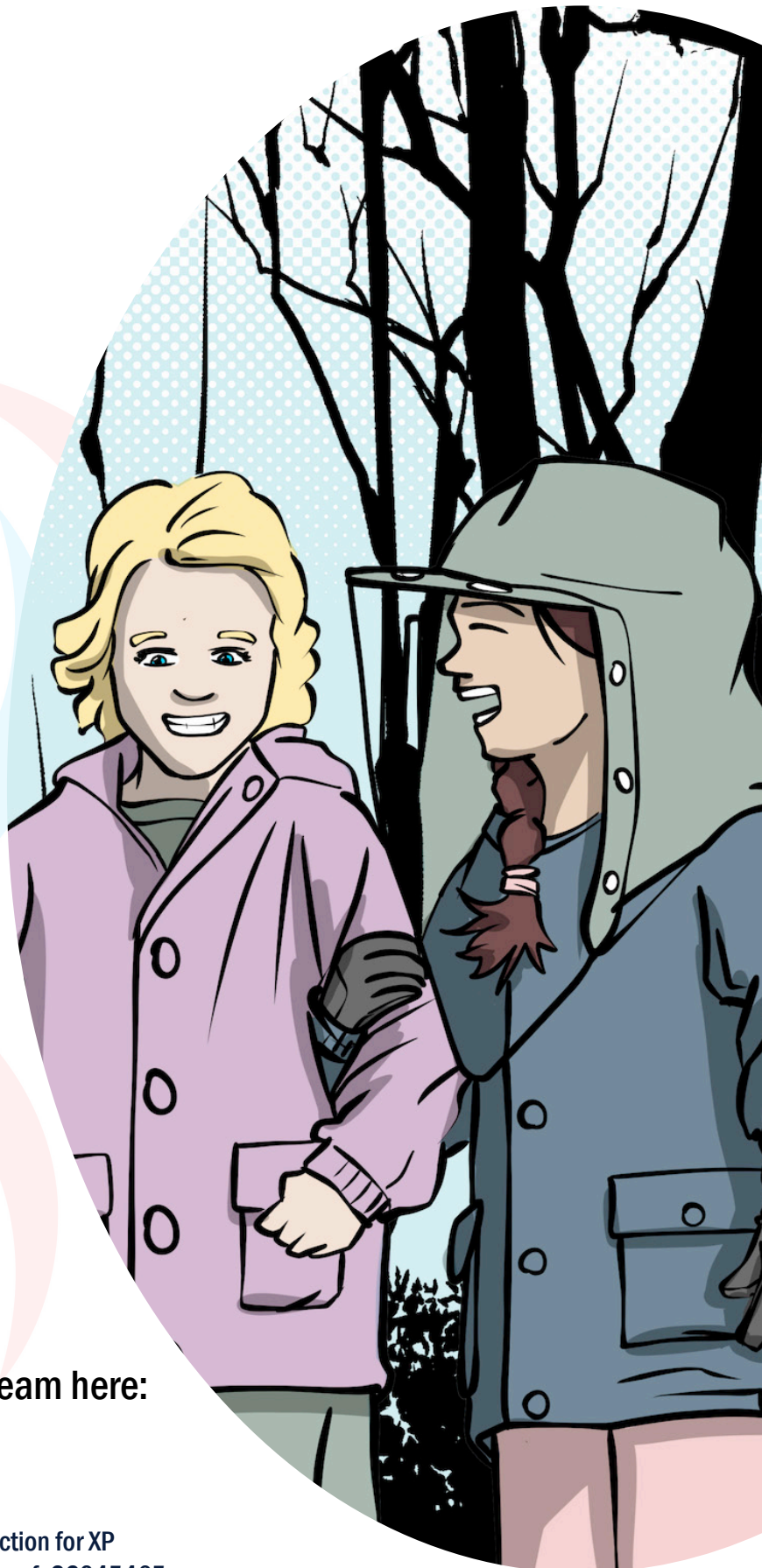
Richard Barlow (Chairperson and XP patient)  
Rebecca Stewart (Treasurer and cofounder)  
Nicola Miller (Secretary and cofounder)  
Annette Dearmun (clinical liaison)  
Ellie McGowan (safe-guarding officer)  
John Roberts  
Wilbur Stewart (cofounder)

Our **volunteers** are the life-blood of our organisation. Supporting the board on a regular basis are the following volunteers:

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

You can find out more about our team here:

[www.actionforxp.org/about-us](http://www.actionforxp.org/about-us)



## About the role

As our Fundraising and Events Officer you would be responsible for driving our short and long-term fundraising and events strategy. This would involve creation and delivery of this strategy. The role will involve a close working relationship with our Operations Officer and our Board of Trustees.

This is an exciting role working with a motivated and committed Trustee team, and a wonderful opportunity to make a big difference!

Key parts of this role include:

### Funding & Administrative Roles:

- Keep in close contact with finance and projects Trustees to identify areas for grant funding
- Source and complete grant applications
- Source and book places on fundraising events
- Create content and liaise with social media volunteers to recruit for event places
- Set up and monitor fundraising portals and pages

### Events:

- Organise own fundraising events
- Creation of promotional materials
- Communicate / market events
- Create fundraising packs for individuals partaking in events
- Monitor other fundraising activities and send thank you letters to fundraisers

### a) Planning:

- Book venues and communicate with venue including:
  - o collating invoices
  - o provision of relevant policies/procedures
  - o manage communication including; liaising re schedules, insurance,
- Research and book activities; design event programme
- Research and book speakers / education
- Create and maintain booking system for attendees

- Organise attendee travel (family, speaker etc)
- Create and assemble attendee/family welcome packs and information
- Source and organise food and refreshments
- Collate parental consent forms
- Purchase all materials needed for activities
- Management of event budgeting

### b) Event Participation:

- On site set up and close down
- Organise transportation of Action for XP materials to and from events

### c) Post-Event Roles:

- Collect and collate post event feedback
- Process volunteer and other attendee expenses
- Collate metrics and report on activities and patient experience in preparation for NHS England review and Board meetings

### Oversee Volunteers:

- Advertise volunteer roles
- Organise interviews and process references
- Conduct and lead volunteer inductions (with support from Safeguarding Trustee)
- Ensure ongoing volunteer engagement
- Support Operations Officer in maintenance of volunteer database

## Key features

**20 hours - remote working**

**Hours of work - Daytime hours TBA**

**Salary pro rata £26k - £32k full time equivalent (depending on experience)**

**28 days pro rata holiday entitlement**

**3 month probation period**

- Occasional evening and weekend working to accommodate for events
- 4-5 conferences and/or events (primarily UK, but may involve international) per year with overnight stays as travel dictates

## Application Process

- Step 1** Interested parties should submit their curriculum vitae and covering letter by **5pm GMT on Monday 11th December**
- Step 2** All applicants will be invited to an open group Zoom call to learn more about our values, work and the role
- Step 3** Applicants interested in progressing with their application will be invited to submit a personal statement and those shortlisted will be invited to attend an individual virtual Zoom interview
- Step 4** Candidates will be shortlisted based on their personal statements and interview. A second interview may be required (on Zoom)
- Step 5** The successful candidate will receive a formal offer of employment and will be required to undergo DBS vetting

**Note:** This opportunity is only open to UK based applicants and we can only consider candidates for this role who have the current legal right to work in the UK.

## Submitting your application

CV and covering letter (maximum two A4 sides) should be submitted in writing to:

[admin@actionforxp.org](mailto:admin@actionforxp.org)

Upon receipt your CV will be reviewed and you will be advised of next steps as per application process as well as the progress of your application.

## Key requirements of the role

**We are looking for an organised, outgoing individual who is able to work independently. Experience in community fundraising and grant bid writing is essential. Experience in events planning is desirable.**

- Proven track record in grant bid writing and community fundraising
- Organised, self-motivated and a flare for problem solving
- Experience in events planning is desirable
- Good working knowledge of Microsoft particularly Word and Excel
- Good coordination skills
- Working knowledge of Canva or other creative software is desirable
- Confident in engaging with Board members, Beneficiaries and the general public

**If you would like to find out more about this role ahead of applying please contact our team at:**

**[admin@actionforxp.org](mailto:admin@actionforxp.org)**

**We look forward to hearing from you!**

