



Support. Educate. Connect.

Recruitment Information Pack

**Operations Officer
(part-time)**

Action for XP
Charity ref: SC045465
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.

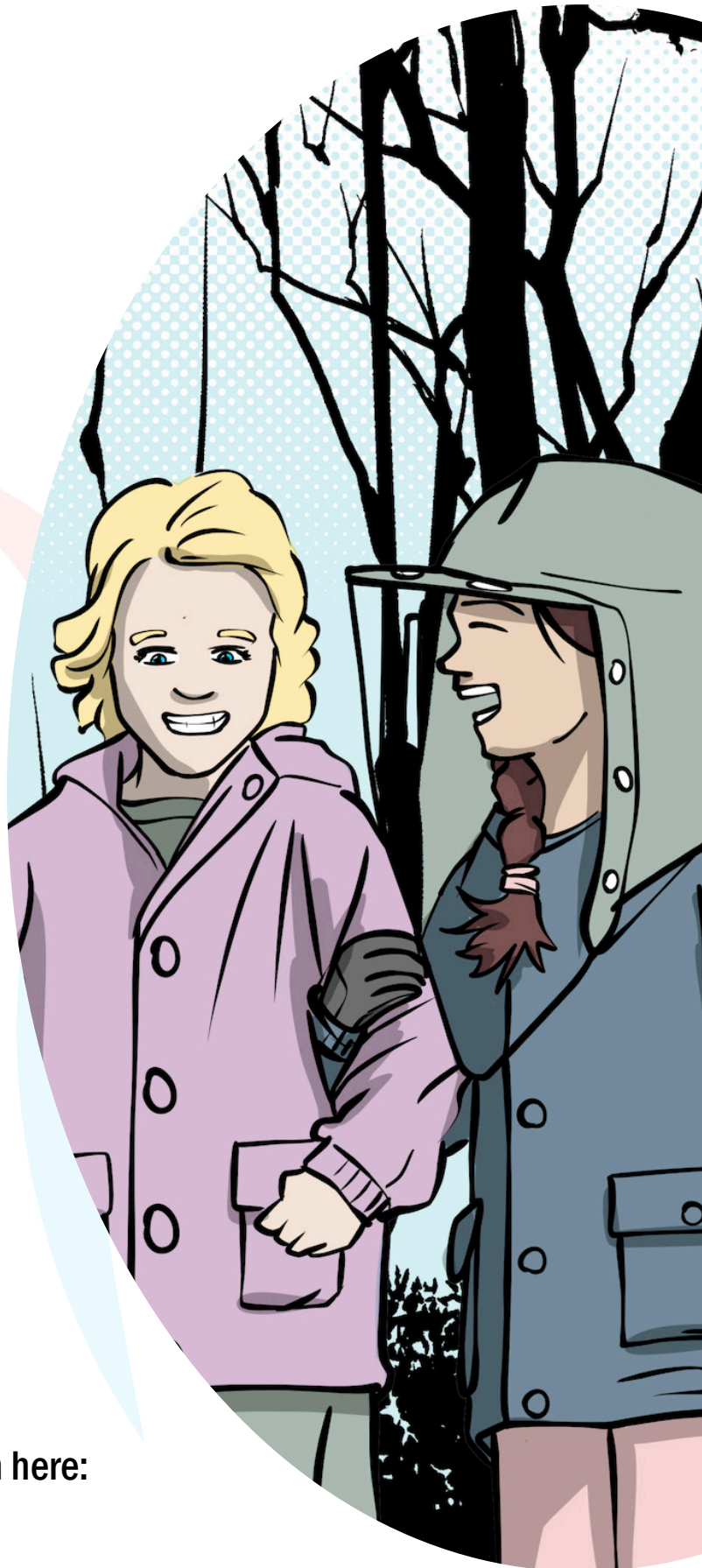
Richard Barlow (Chairperson and XP patient)
Rebecca Stewart (Treasurer and cofounder)
Nicola Miller (Secretary and cofounder)
Annette Dearmun (clinical liaison)
Ellie McGowan (safe-guarding officer)
John Roberts
Wilbur Stewart (cofounder)

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



About the role

As our Operations Officer you would be responsible for the day-to-day operational activities of the organisation focused on patient support and project delivery. The role will involve a close working relationship with our Fundraising and Events Officer, and our Board of Trustees, and will be a pivotal role within our small but mighty organisation.

This is an exciting role working with a motivated and committed Trustee team, where you will be driving forward the organisations mission and making a big difference!

Key parts of this role include:

Patient Liaison:

- Respond to email enquiries
- Liaise with schools
- Work in conjunction with Clinical Liaison Trustee to report to multidisciplinary clinic in London (no clinical knowledge or responsibility expected or required)
- Process and send thank you acknowledgments and bereavement cards
- Attend key awareness and engagement events

Patient Support:

- Coordinate patient resource requests
- Communicate with courier and process and submit customs paperwork
- Liaise with volunteers on fulfilment of patient shipping requests
- Renew DHL agreements for shipping
- Complete DLA / PIP (templates available) and tribunal paperwork
- Support blue badge applications
- Process patient protection grants
- Order stock in liaison with Treasurer
- Liaise with international patient groups for collaborative aid or project efforts

Project Delivery

- Work closely with Trustees to execute delivery of projects and track progress
- Communicate funding needs to Fundraising Officer
- Coordinate input from project contributors
- Disseminate project output via dedicated campaigns and communications
- Create feedback processes and collate and report insights to Board

Administrative Duties:

- Attend Board meetings, generate agenda, take minutes and distribute.
- Generate Trustee and impact reports
- Disseminate information to volunteers
- Create Trustee Logs for expenditure
- Maintain records of training and DBS for staff, volunteers and Trustees
- Create monthly newsletters
- Oversee and execute social media campaigns
- Manage social media channels and liaise with social media volunteers
- Work with Trustees to maintain and ensure website remains current
- Support the Fundraising and Events Officer in delivery of events

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 international beneficiaries and events
- 4-5 conferences and/or events (primarily UK, but may involve international) per year

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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

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 a self-motivated, organised and driven individual who is able to work independently. Due to the family support nature of this role applicants must be caring and empathetic by nature and able to handle situations of a sensitive nature.

- Organised, self-motivated and a flare for problem solving
- Able to project manage/coorindinate multiple workstreams
- Good working knowledge of Microsoft particularly Word and Excel
- Good working knowledge of social media platforms Facebook and Twitter
- Working knowledge of Canva or other creative software
- Confident in engaging with Board of Trustees and Beneficiaries

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

admin@actionforxp.org

We look forward to hearing from you!

