

Trustees' Annual Report

Foundation to Overcome Rare Genetic Errors (FORGE)

For the year ended 31 December 2024

1. Objectives and Activities

The Foundation to Overcome Rare Genetic Errors was established with the charitable purpose of preserving and protecting the good health for the public benefit by providing grants to support research into rare genetic disorders, particularly, though not exclusively, childhood autoinflammatory conditions.

The charity aims to:

- Improve the lives of those affected by rare genetic conditions.
- Support research to correct gene errors causing disease.
- Deepen scientific understanding of these conditions.
- Develop better methods of monitoring disease activity.
- Disseminate research findings for public benefit.

During its first full year of operation, the Trustees have focused on establishing the charity's governance and operational structures, engaging expert collaborators, developing partnerships, and initiating early fundraising and outreach activities.

2. Achievements and Performance

Establishing Foundations

The Trustees are pleased to present FORGE's first annual report, reflecting the significant progress made during 2024. This inaugural year has been instrumental in building the operational framework of the charity and creating the foundations needed to achieve its charitable objectives.

The Trustees have also gained valuable insight into the global landscape of rare genetic diseases, enabling a deeper understanding of the needs of those affected and the opportunities for research and advocacy.

The work of FORGE is guided by a commitment to accelerate scientific research while also supporting advocacy and compassionate care for families. Rare genetic disorders, often referred to as 'orphan diseases,' affect only a small proportion of the population and are frequently overlooked by mainstream healthcare and research systems. FORGE is determined to change that.

3. Engaging with Leading Experts and Researchers

As part of our strategic focus on building scientific credibility and fostering collaboration, FORGE has prioritised engagement with leading international experts and research institutions. Establishing these connections has been a key element of our first year's activity, ensuring that the charity's future initiatives are informed by the most advanced global expertise in immunology, genetics, and rare disease research.

As part of our commitment to scientific progress and community-informed collaboration, FORGE has made contact during 2024 with a wide network of international experts and researchers working across fields relevant to rare genetic conditions. These relationships have begun to establish the foundation for future collaboration, knowledge exchange, and joint research initiatives. Where lists have been produced, they are arranged in alphabetical order.

United States

FORGE has developed connections with several leading institutions in the United States that are at the forefront of research into immunology, genetics, and paediatric medicine:

- **National Institute of Allergy and Infectious Diseases**, Bethesda, Maryland
- **Stanford University**, Institute for Stem Cell Biology and Regenerative Medicine, California
- **Stanford Medicine**, Division of Paediatric Haematology, Oncology, Stem Cell, Transplantation and Regenerative Medicine, California
- **University of Pennsylvania**, Institute for Immunology and Immune Health, Philadelphia

United Kingdom

Our UK collaborations span major centres of excellence in paediatric and immunological research, strengthening our links with national academic and clinical partners:

- **Great Ormond Street Hospital for Children NHS Foundation Trust**, Department of Paediatric Rheumatology, London
- **Imperial College London**, Departments of Immunology and Inflammation, Infectious Disease and the School of Public Health, London
- **Institute of Genetics and Cancer**, The University of Edinburgh, Scotland.
- **National Heart and Lung Institute**, Imperial College London
- **Royal Brompton Hospital**, Departments of Paediatric Respiriology and Adult Respiratory Medicine, London
- **UCL Great Ormond Street Institute of Child Health**, Department of Infection, Immunity and Inflammation, London
- **University College London**, Infection, Immunity and Inflammation Department, London

Australia

Recognising the strong research environment in Australia, FORGE has engaged with leading institutes and clinicians across Melbourne, Brisbane, and Sydney:

- **Centre for Child Health Research and Innovation**, University of New South Wales
- **Hudson Institute of Medical Research**, Innate Immune and Autoinflammatory Disease Division, Melbourne
- **Monash Health**, Clinical Genetics, Melbourne
- **Murdoch Children's Research Institute**, Melbourne
- **Queensland University of Technology**, School of Biomedical Sciences, Brisbane
- **Royal Children's Hospital**, Departments of Allergy and Immunology, Rheumatology, Respiratory Medicine and Genetics, Melbourne
- **Walter and Eliza Hall Institute**, Inflammation Division, Melbourne

Other International Research Centres

FORGE has also initiated dialogue with leading international experts and centres of excellence across Europe, including:

- **Hôpital Necker–Enfants Malades**, Service d'Immuno-Hématologie et Rhumatologie Pédiatriques, Paris, France
- **IMAGINE – Institut des Maladies Génétiques**, Neurogénétique et Neuroinflammation, Paris, France
- **Karolinska Institutet**, Department of Women's and Children's Health, Stockholm, Sweden
- **University Children's Hospital Ljubljana**, Department for Paediatrics, Slovenia
- **University Hospital Münster**, Section of Rheumatology and Clinical Immunology, Münster, Germany

These engagements collectively represent a growing global network of clinicians and scientists who share our commitment to advancing the understanding, diagnosis, and treatment of rare genetic diseases. This developing network will underpin future collaborative projects, knowledge sharing, and opportunities to direct funding towards high-impact research initiatives that align with FORGE's mission.

4. Initiating Collaborations with Leading Organisations

As part of our wider strategic development, the Trustees have actively sought to build partnerships with organisations that share FORGE's vision for innovation, research, and patient advocacy. These early-stage collaborations are designed to identify opportunities for joint projects, shared learning, and collective impact across the rare disease landscape.

Research and Academic Partners

FORGE has established contact with a range of academic and research networks committed to advancing understanding of rare genetic and autoinflammatory diseases.

Key engagements include:

- **Imperial College London** (specifically Department of Public Health, Epidemiology and Biostatistics). Imperial which ranks top in the UK overall for research, with a greater proportion of world-leading research than any other UK University.
- **International Consortium on Newborn Screening (ICONS)**, a global initiative working to harmonise and advance newborn screening programmes for early detection of genetic and metabolic disorders.
- **Genomics England**, a government-owned organisation supporting genomic research and its integration into healthcare.
- **Translational Autoimmune Research Network (TARN)**, an international collaborative network dedicated to advancing translational research in autoimmune and autoinflammatory conditions.

These connections are helping to identify areas of shared research interest and future collaboration that will contribute directly to improved diagnostic and therapeutic outcomes.

Pharmaceutical and Industry Partners

FORGE has also begun dialogue with researchers and industry representatives focused on translational science, biotechnology, and therapeutic development. Engagements to date have included:

- **Alnylam Pharmaceuticals**, United States
- **Ilya Pharma**, Sweden

These discussions are intended to explore the interface between scientific discovery and clinical application, with a view to supporting research that can translate into real-world treatments for rare genetic conditions.

Charitable and Advocacy Organisations

Recognising the vital role of the charitable and advocacy sector in driving awareness and patient support, FORGE has developed relationships with peer organisations whose missions align closely with our own.

Key partnerships and engagements have included:

- **Auto-Inflammatory Alliance**
- **Childhood Interstitial Lung Disease UK**
- **Genetic Alliance UK**
- **Juvenile Arthritis Foundation Australia**
- **Rare Voices Australia**
- **UK Inflammatory Bowel Disease Registry**

These relationships aim to strengthen the collective voice of families affected by rare diseases and to promote coordinated advocacy for improved access to research, information, and care.

Professional and Operational Support

In addition to sector partnerships, FORGE's work has been supported by professionals and organisations offering reduced or pro bono consultancy in key operational areas.

Contributors include:

- **Alex Hayes**, *The National Lottery Community Fund*, fundraising
- **Baker McKenzie LLP**, legal
- **Ecovia**, operational
- **Fusion Pharma**, regulatory
- **Giselle Okin**, *Opinionated Thinking*, brand strategy
- **Hatched**, website
- **Hussein Al-Mossawi**, *AstraZeneca*, research
- **Janita Patel & Alex Bryne**, branding
- **Jen Kay**, social media
- **Fezzan Ahmed**, *Jigsaw House Society*, philanthropy and strategy
- **Laura Sands**, copywriting
- **Paul McKenzie**, *Giant Steps Fundraising Consultancy*, fundraising and strategy
- **Rob Hare Design**, graphic design and branding
- **Roger Brooks**, *University of Cambridge*, research
- **Roya Haghighat-Khah**, *MedAccel*, research and regulatory
- **Sophie Spencer Wood**, image editing

Their contributions have been invaluable in guiding governance, communications, design, and strategic planning, helping to position FORGE for long-term impact. These collaborations reflect the strong early foundations of FORGE's partnership strategy. By engaging leading organisations across academia, industry, and the charitable sector, we are building a robust framework for future joint initiatives that will accelerate research, strengthen advocacy, and enhance outcomes for families affected by rare genetic disorders.

5. Enhancing Online Presence and Technological Capabilities

As part of our operational development in this first year, FORGE has taken important steps to establish a visible and effective online presence. A strong digital framework is essential for connecting with beneficiaries, supporters, and collaborators, and for ensuring the charity's activities are accessible to a global audience.

Website and Digital Infrastructure

With pro bono support, FORGE launched an initial holding website, incorporating a donation platform powered by Stripe. This provided an early digital presence for information sharing and donor engagement.

During 2024, work began on the development of a comprehensive full website to reflect the charity's growing activities and partnerships. A team of professionals and volunteers contributed to this project, providing support across:

- Content development and copywriting
- Social media setup and integration
- Image sourcing and visual branding
- Graphic design, logo development, and professional web design

These collective efforts have strengthened FORGE's identity and will provide a platform to communicate our mission, research priorities, and fundraising activities.

Networking and Information Resources

In parallel, FORGE benefitted from the contribution of a molecular geneticist based in Turkey, who compiled a global directory of experts in gene editing and interferonopathies. This resource now supports the charity's developing scientific network and has enhanced our ability to identify and engage with relevant research leaders worldwide.

Communications and Outreach

Through the creation of a digital communications framework, FORGE is now positioned to engage its community more effectively. These developments have enabled the Trustees to share updates, research progress, and patient-focused information in a timely and accessible way.

These early technological and communication developments represent an important investment in FORGE's capacity to connect, inform, and engage. Our enhanced online presence not only supports fundraising and collaboration but also reinforces our commitment to transparency, accessibility, and the dissemination of knowledge within the rare disease community.

6. Fundraising and Volunteer Recruitment

FORGE's first year has seen encouraging progress in building community support through early fundraising events and volunteer engagement. These activities have not only provided initial financial contributions but have also helped to establish a sense of shared ownership and participation among those who believe in the charity's mission.

Community Fundraising Events

In its early stages, FORGE has benefitted from a number of community-driven events that have raised both awareness and essential funds to support our charitable objectives:

- **Charity BBQ and Musical Recital** (August 2023, pre-incorporation)
- **Family Fun Day** (September 2024)

These events provided valuable early resources and created opportunities to connect directly with supporters, fostering community spirit around the charity's aims.

Volunteer Recruitment and Contributions

During its first year, FORGE has been fortunate to recruit two senior scientific and medical advisors. **Dr Roger Brooks** and **Dr Roya Haghighat-Khah**, have provided expert insight and ongoing clinical guidance.

Additional volunteer support was provided by **Rathna Pillai**, **Shaila Bates**, **Rhys Bates**, **Kothanayagi Brodbeck**, and **Sheryl Moore**, who have played key roles in coordinating fundraising events and community engagement initiatives.

A workplace meal service established by **Krishna Hyer** has also been running successfully for six months, generating regular contributions while promoting awareness of FORGE's mission.

Strategic Development

Alongside these community efforts, the Trustees have continued to develop the charity's strategic framework to ensure sustainable growth and alignment with its long-term goals. Key achievements during this period include:

- Development of a comprehensive funding strategy.
- Submission of a grant application to the **Sir Halley Stewart Trust**.
- Development of the **FORGE Connect** initiative to strengthen collaboration between researchers and families.
- Raising awareness through educational materials and bioPixel prints of the *TMEM173 (STING1)* gene.

Through these early fundraising and volunteer initiatives, FORGE has built a strong foundation of goodwill and participation. The Trustees recognise and sincerely thank all those who have given their time, expertise, and resources to advance the charity's mission. This collective effort has provided both the financial and organisational platform upon which FORGE will continue to grow in the years ahead.

7. Legal Foundation and International Development

FORGE achieved a major milestone in 2023 with its formal registration as a Charitable Incorporated Organisation (CIO) with the Charity Commission for England and Wales. This registration, completed on 14 December 2023, established the legal framework through which the charity is governed and operates.

Expanding International Reach

In recognition of the global nature of rare genetic disease, work is also underway to establish FORGE Australia, which will extend the charity's impact internationally and enhance opportunities for collaboration. Legal support for this process has been provided pro bono by **Baker McKenzie LLP**, whose expertise has been invaluable in guiding the development of our international structure.

As part of this process, FORGE have recruited two future Directors for FORGE Australia:

- **Liz Vuletich**, Neuropsychologist and Director of MindLink Psychology
- **Sam Stuart**, Director and Services Business Lead, Security Solutions, Mastercard

Their combined experience, both through personal lived experience of rare genetic disease and professionally across the health and corporate sectors, will be instrumental in shaping the direction and governance of the charity's Australian branch.

Purpose and Benefits of Expansion

Establishing a presence in Australia reflects the charity's recognition that the rare disease community is inherently international, and that collaboration across borders is essential to driving progress. This development will:

- Enable FORGE to engage directly with leading researchers and clinical centres in Australia and the wider Asia-Pacific region.
- Provide a legal and operational foundation for cross-border initiatives and shared funding opportunities.
- Provide access to new fundraising and revenue streams specific to Australia, drawing on the charity's growing network of local supporters and potential donors.
- Allow FORGE to reach and support families and beneficiaries who may otherwise remain isolated from key networks of expertise and support.

This legal and constitutional development marks a pivotal step in FORGE's evolution from a newly registered UK charity to an emerging international organisation. The Trustees recognise that this foundation is essential for ensuring effective governance, broadening the charity's reach, and supporting long-term sustainability as we continue to pursue our mission to advance research and support for those affected by rare genetic disorders.

8. Collaboration with Patient Advocacy Groups

FORGE has recognised from its first year the importance of placing the voices of patients and families at the centre of everything we do. Meaningful collaboration with patient communities is fundamental to achieving our mission of supporting those affected by rare genetic conditions and ensuring that research remains grounded in lived experience.

Building Partnerships with Advocacy Communities

During 2024, FORGE was active in the **SAVI Warriors** Facebook patient group, which brings together families affected by the rare autoinflammatory condition SAVI. This provided valuable insight into the experiences, challenges, and priorities of families living with rare genetic disease.

Through this platform, the charity has:

- Conducted surveys and gathered patient stories for inclusion on the FORGE website.
- Begun building relationships that will underpin future collaboration and ensure that patient perspectives remain central to our advocacy and research priorities.

Creative Representation and Public Awareness

As part of its commitment to advocacy and public engagement, FORGE submitted an image to Genetic Alliance UK for their publication *More than You Can Imagine: An Anthology of Rare Experiences*. The submission, titled *Inexpressible suffering but inextinguishable hope*, was accompanied by the following reflection:

'The energy and relentlessness of the passage of time. The chaos. The beauty. As strategic and technical as the solution will be, the journey is still very much a raw emotional one. FORGE represents the future. Connection. Collaboration. Advocacy.'

This contribution reflects the emotional and human dimension of FORGE's mission, conveying both the hardship and the hope that define the rare disease experience.

Working with **Melbourne Genomics**, FORGE also produced a video featuring personal family reflections on childhood rare disease (SAVI). This project aims to increase public awareness and understanding, helping to bridge the gap between medical research and real-world impact on families. This was developed to celebrate 10 year review of genomics in Victoria, Australia.

FORGE initiated discussions with the **Fresh Heart Project** regarding the development of a short art film to raise awareness of rare diseases and their impact on families. This exploratory project represents a creative new avenue for advocacy and public engagement.

Communications and Community Building

To strengthen communication with supporters, FORGE is developing a **Mailchimp newsletter** to share updates, highlight ongoing initiatives, and invite participation from families and partners. This platform will continue to evolve as the charity's patient network grows.

Embedding the Patient Voice

These initiatives have strengthened FORGE's commitment to ensuring that patients and families are not only beneficiaries of research but active contributors to its direction and

purpose. The insights gained from these collaborations will continue to inform the charity's approach to advocacy, funding priorities, and communication.

By building trusted relationships with patient advocacy groups, FORGE has laid the foundation for a community-centred model of engagement. These partnerships ensure that the lived experience of those affected by rare genetic conditions remains central to our strategy and will continue to shape the charity's development in the years ahead.

9. Plans for the Future

Looking ahead, the Trustees will continue to build on the strong foundations established during FORGE's first year. The focus for the coming period will be on expanding our partnerships, strengthening our research and advocacy networks, and developing the organisational capacity needed to sustain long-term impact.

Strategic Priorities for 2025

Key areas of focus will include:

- **Expanding research collaborations:** Building on relationships established during 2024 with leading researchers and institutions to initiate joint projects, promote knowledge sharing, and identify new research opportunities that align with FORGE's mission.
- **FORGE CONNECT:** This initiative will build a global network connecting patients, families, clinicians, and researchers affected by rare genetic autoinflammatory disorders, beginning with the SAVI community. Its aim is to identify and reach all individuals and families affected by SAVI worldwide, fostering communication, shared experience, and collaboration between patients and researchers. Through FORGE CONNECT, the charity will ensure that the patient voice directly informs research priorities and advocacy.
- **Establishing a Scientific Advisory Board:** Creating a formal Scientific Advisory Board to guide FORGE's research strategy, provide expert oversight, and appraise applications for research grants and collaborations, ensuring that all supported work meets the highest standards of scientific and ethical integrity.
- **Enhancing digital infrastructure:** Completing the development of the full FORGE website and expanding the charity's digital platforms to improve accessibility, and enhance engagement with patients, supporters, and collaborators.
- **Developing sustainable funding streams:** Pursuing grant funding, donor partnerships, and community fundraising initiatives to ensure the long-term financial stability of the charity.
- **FORGE Australia registration and launch:** Finalising the legal establishment of FORGE Australia and commencing its first programme of activities in collaboration with its newly appointed directors and advisors.

The year ahead represents a period of consolidation and growth for FORGE. With a strong foundation of partnerships, community support, and strategic direction, the charity is well

placed to advance its mission, strengthen its global presence, and make a meaningful contribution to the rare disease community.

10. Closing Statement

The Trustees are proud of the progress made during this first year in establishing FORGE as a credible, collaborative, and compassionate force for change. Our growing partnerships, strengthened infrastructure, and deepening community engagement provide a strong platform for advancing research and supporting individuals and families affected by rare genetic conditions as we move beyond 2024.

Equally important has been our developing understanding of the central role of patient advocacy. We remain committed to placing the lived experiences of individuals and families at the heart of everything we do. A key focus of our future planning will be to build genuine and sustained engagement between patients and the research institutions developing new treatments, ensuring that those most affected help to shape the direction of progress. By giving families a voice and amplifying their stories, FORGE aims to build a more inclusive, informed, and empowered community for those navigating life with rare genetic disorders. FORGE was founded out of a personal reflection on a rare disease diagnosis — how can you live day to day with profound uncertainty and without hope? The answer is that you cannot: you need hope, and hope needs a plan.

The Trustees are confident that FORGE has a distinctive and vital role to play in the global rare genetic landscape, and we look forward with optimism and purpose to what can be achieved in the years ahead.

11. Structure, governance and management

The annual report was approved by the trustees of the charity on 24 October 2025.

Signed on behalf of the Trustees:

A handwritten signature in black ink, appearing to be 'J Hyer', written in a cursive style.

Dr Jonathan Hyer BA(Hons) MBBS FRCOphth
Trustee, Foundation to Overcome Rare Genetic Errors
24 October 2025

