

Chronic Granulomatous Disorder Society

**Strategy
2025 -2028**

About us

At the heart of the CGD Society lies a powerful truth: while Chronic Granulomatous Disorder (CGD) is rare, the strength, resilience, and unity of those it affects are extraordinary.

Founded over three decades ago, the CGD Society has grown from a small parent-led support group into a globally recognised charity. We are dedicated to providing trusted information, compassionate care, and a powerful voice for advocacy for individuals and families affected by CGD. Our journey has been driven by a vision of a world where CGD no longer defines lives, but rather, allows every individual affected to thrive with health, dignity, and hope.

CGD is a complex and life-limiting condition that requires lifelong management, early diagnosis, and access to specialist care. Families often face isolation, uncertainty, and a lack of awareness from both the public and healthcare professionals. The CGD Society is committed to addressing these challenges by fostering a supportive community, raising awareness, and advancing research and treatment options.

As we look ahead, our mission remains clear: to improve the lives of those affected by CGD and to work tirelessly towards a future where the burden of this condition is lessened, and ultimately, eradicated. Together, we strive for a brighter future for all those touched by CGD.



Our highlights



1,952
Membership in
2024/25



Active across 81
countries



35% of our
2024/25
membership,
including
extended family,
are affected by
CGD.



831 Members
from the UK, 494
USA and 648 other



Increase of 205
members in
2024/25



Average 21,000
visits to our
website in
2024/25



£28,000 Achieved in
fundraising in
2024/25



14 Newsletters
communicated last
year



Total income
£360K in
2024/25

Introduction - Executive Director



Claire Liddle
Executive Director - CGD Society

It is with great pride that I introduce The CGD Society's Strategy for the next three years. As Executive Director, I am honoured to lead an organisation dedicated to improving the lives of those affected by Chronic Granulomatous Disorder, a rare condition that demands both resilience and community.

Our mission remains clear: to provide trusted information, meaningful support, and to advocate for advances in care and treatment. This strategy builds on our strong foundation and sets out a clear roadmap to meet the evolving needs of our community

As we look ahead, it is also important to pause and celebrate our successes to date. The unwavering commitment of our nursing provision, the creativity and hard work of our fundraising teams, and the positive impact of our charitable support offers have all made a real difference in the lives of those we serve.

I would also like to express our heartfelt thanks to our incredible community of corporate partners and supporters, whose energy and generosity power so much of what we do. From walking and running events to local community fundraising activities, every contribution, large and small, plays a vital role in enabling our mission. Your dedication inspires us and strengthens the fabric of the CGD Society.

Together, through collaboration, compassion, and shared purpose, we will continue to make strides for everyone affected by CGD.

Introduction - Chair of the Board of Trustees



Wayne Kitchener
Chair of the Board of Trustees –
CGD Society

The Chronic Granulomatous Disorder (CGD) Society's new three-year strategy, is a clear and ambitious roadmap focused on building our community, raising awareness, and bringing together the rare disease's community.

First, I want to sincerely thank our entire community, members, families, clinicians, researchers, and supporters. Your resilience, generosity, and shared commitment continue to shape the heart of the CGD Society. Without your trust and support, none of what we have achieved would be possible.

I also want to acknowledge the dedication of our trustees and staff, whose hard work and leadership have ensured the charity remains strong and forward-looking. Their expertise and compassion have shaped this strategy and will guide us in the years ahead.

Over the next three years, we will strengthen our support networks, improve how we connect and empower those living with CGD, and raise awareness of the challenges of both CGD and rare diseases more broadly. By collaborating more closely with partners across the rare disease community, we aim to amplify our collective voice and create greater understanding, improved care, and more opportunities for those we serve.

Our ambitions are clear, to grow a stronger, more inclusive charity that offers connection, education, and advocacy to all affected by CGD. We step into the future with energy, confidence, and hope, inspired by the community we are privileged to serve.

Thank you for standing with us. Together, we will continue to build something remarkable.

Building a stronger future for the CGD Community

This strategy addresses challenges and seizes opportunities. It is built on four principles: helping our community, advocating for CGD awareness, promoting research, and raising funds. These aims are commitments to those we serve. We will strengthen nursing and clinical partnerships, expand support services, amplify voices of those with CGD to drive change, and support research.

Through strategic partnerships, digital transformation, and initiatives like Jeans for Genes, we will grow our impact and ensure financial sustainability. This journey honours our community's courage, our supporters' dedication, and the vision of a world free from the challenges of CGD.

The CGD Society's 2025–2028 strategy recognises the challenges and opportunities in our operating environment. CGD requires lifelong care and specialist support. Barriers to access, limited awareness, and gaps in clinical understanding persist. Economic uncertainty and rising healthcare demands further complicate the landscape.

To succeed, we must embrace new ways of working, explore diverse funding and financial options, expand and build new partnerships whilst explore the opportunities of technology. We will continually evaluate our progress through a variety of KPIs ensuring a continuous improvement approach coupled with ongoing collaboration with our partners, community and staff.

This strategic context demands resilience, innovation, and collaboration. The CGD Society is ready to meet these demands, guided by our mission, inspired by our community, and committed to a future where no one faces CGD alone.

Your achievements

Becca's 10k run



Rebecca was due to run the Great South Run on 20th October in support of our charity, but the event was sadly cancelled due to bad weather. Undeterred, she took to her local area and completed the run anyway, braving the rain, getting soaked, and still finishing with a smile.

The CGD Society has been supporting my family since October 2022, when my son Elliot was diagnosed with CGD. They have been there through every hospital admission, every setback, every step of Elliot's transplant - always answering questions and providing any kind of support we need

Alex's run and cycle across Scotland



Alex covered an astonishing 23 miles on foot and 80 miles on and off road by bike, starting in Nairn and finishing in Glencoe. He completed the course in an incredible 11 hours and 40 minutes, placing 35th out of 400 participants, **raising nearly £6,500 to help CGDS.**

Alex said: "My nephews Ben (10) and Bobby (9) have a very rare genetic disease called CGD and have spent years under the care of specialists at Great Ormond Street Hospital

Southwest Hertfordshire's annual Vintage Sports Car Club BBQ



Ian Cheese and the wonderful community of car enthusiasts from the SW Hertfordshire Vintage Sports Car Club, who once again hosted their annual summer BBQ in support of CGD Society.

The event raised an **amazing £681** and was held in honour of two brave young brothers - Bobby, who is currently undergoing treatment for CGD and Ben, who has successfully completed his treatment.

The CGD Society Team



From left to right: Claire Liddle (Executive Director), Catherine Bean (Fundraising and Marketing Manager), Blessing Ikaka (Trustee), Maria Loughenbury (Trustee), Wayne Kitchener (Chair), Josh Stevens (Treasurer), Chikai Lai (Trustee), Kumar Perampaladas (Trustee), Sarah Robertson (Trustee) and Helen Braggins (CGDS Specialist Nurse).

CGD Society

Supporting families affected by
chronic granulomatous disorder

Our Golden Threads

Our "**Golden Threads**" underpin our four guiding principles that guide all the society's work. They represent the essential, interconnected themes that run through every objective, initiative, and partnership.



Advocacy and knowledge



Communications and marketing



Financial sustainability & growth

Our Vision



Our vision for CGD, is a future free from its challenges, where every individual thrives in good health.

Mission Statement

Our mission is to support individuals, families, and communities affected by CGD by providing guidance, care and advocacy.

We will drive research, innovation, and partnerships to work toward better treatments, access and knowledge whilst empowering individuals.



Chronic Granulomatous Disorder Society

Our
strategic
guiding
principles

Guiding Principles Helping our community

What will this mean for you?

- We will work with experts to share guidance and trusted information, empowering you to make informed decisions about your health and well-being.
- We will work with the NHS to develop dedicated acute medical support through our trusted partnership with the NHS, ensuring timely and comprehensive care when it's needed most.
- We will work with partners to create access to holistic support services designed to meet the needs of the entire family, fostering resilience and unity within the CGD community.
- We will cultivate a strong platform for collaboration, empowering the community to come together, share experiences, and build enduring local connections.



Guiding Principles - Advocate for the CGD community



What will this mean for you?

- We will champion awareness of CGD by showcasing our work and amplifying our impact across the life sciences, medical, and political arenas, advocating for meaningful advancements and systemic support.
- We will ensure the CGD community has a prominent seat at the table, empowering them to actively shape policies, influence decision-making, and drive transformative change.
- We will foster deep collaboration with the CGD and wider rare diseases community, uniting efforts to raise awareness, share compelling stories, and advocate for their needs and rights.

Guiding Principles – Promote scientific research, innovation and best practice.

What will this mean for you?

- We will drive awareness of CGD by highlighting our work and advancing our impact across the life sciences, medical, and policy sectors, championing innovative solutions and research breakthroughs.
- We will empower the CGD community by amplifying their voice and fostering meaningful dialogue to influence policy and drive systemic change.
- We will collaborate closely with the CGD community, researchers, and innovators to share compelling stories, inspire action, and accelerate scientific advancements that improve lives.



Guiding Principles - Raise funds to support a better future



What will this mean for you?

- We will launch impactful, results-driven campaigns to significantly enhance our fundraising capabilities, ensuring sustainable growth and increased reach.
- We will strategically expand and cultivate diverse fundraising partnerships, building strong, mutually beneficial relationships with organisations, donors, and stakeholders.
- We will create meaningful change by empowering and supporting the rare disease community through the transformative impact of our Jeans for Genes (J4Gs) programme.

Chronic Granulomatous Disorder Society

Achieving
our
strategic
aims

Achieving our Strategic Aims

Helping our community

Driver	Aim	Impact
Enhance Nursing Services through Strategic Partnerships	Recommission and optimise our nursing service in collaboration with the NHS and Great Ormond Street Hospital (GOSH) to improve patient care and service delivery.	A secured nursing contract for the next three years ensures continuous, high-quality patient care and stability in service delivery
Strengthen Nursing Provision for Maximum Impact	Conduct a comprehensive review of our nursing provision with NHS partners and specialist nurses to ensure an expanded and effective service offering, creating a centre of excellence for CGD.	Expanded access to clinical services and early intervention leads to timely diagnoses and improved health management.
Expand Clinical Education for Improved CGD Awareness and Support	Develop and enhance clinical education programmes that promote awareness of Chronic Granulomatous Disease (CGD), facilitate early diagnosis, and provide essential information to support affected individuals.	Increased knowledge of CGD among clinical groups enhances patient care, ensuring better access to specialized treatment.
Co-Design and Simplify Access to Support Services	Collaborate with the CGD community to develop and deliver accessible support services, including clinical guidance, financial assistance, mental health resources, and grief support.	Improved access to services and an expanded CGD community offer provide comprehensive care and resources for patients and families.

Achieving our Strategic Aims

Promote scientific research, innovation and best practice

Driver	Aim	Impact
Increase Awareness and Impact	Drive awareness of CGD by showcasing our work and demonstrating our impact across the life sciences, medical, and policy sectors. Highlight our role in championing innovative solutions and research breakthroughs to elevate CGD's visibility.	By highlighting our work and advancing our impact across the life sciences, medical, and policy sectors, CGD becomes a recognised leader in driving innovative solutions and research breakthroughs, ultimately transforming lives and shaping the future of the field.
Empower the CGD Community	Empower the CGD community by amplifying their voice and fostering meaningful dialogue to influence policy and advocate for systemic change that supports the community's needs.	Amplifying the voice of the CGD community fosters a platform for meaningful dialogue that influences policy decisions and drives systemic change, ensuring better support, recognition, and resources for CGD patients and their families.
Foster Collaboration and Inspire Action	Collaborate closely with the CGD community, researchers, and innovators to share compelling stories, inspire action, and accelerate scientific advancements that lead to tangible improvements in lives affected by CGD.	Close collaboration with the CGD community, researchers, and innovators accelerates the development and sharing of groundbreaking stories and scientific advancements, translating research into real-world solutions that significantly improve the quality of life for those affected by CGD.

Achieving our Strategic Aims

Raise funds to support a better future

Driver	Aim	Impact
Fundraising Strategy Development and Integration	Develop and implement a comprehensive fundraising strategy incorporating individual donations, corporate partnerships, and grant activities to enhance CGDS's financial stability and sustain its service offerings and community impact.	By developing and embedding a robust fundraising strategy that includes individual, corporate, and grant activities, CGDS will secure the financial stability necessary to sustain and enhance its services, ensuring long-term positive impact on the CGD community.
Launch J4Gs 3-Year Fundraising Campaign	Initiate and lead the J4Gs 3-year fundraising campaign, in collaboration with Upward Communications, to raise awareness about rare diseases and generate financial support for the broader J4Gs grant programme.	The successful launch and execution of the J4Gs 3-year fundraising campaign, in partnership with Upward Communications, will raise significant awareness of rare diseases and provide critical financial support to the J4Gs grant program, directly benefiting the wider CGD community.
Achieve Financial Sustainability and Growth	Work towards achieving financial sustainability over the next three years, positioning CGDS for growth to better support the CGD community and expand the organisation's mission and impact.	Through efforts to achieve financial sustainability and growth over the next three years, CGDS will strengthen its ability to expand support and resources for the CGD community, enhancing both the reach and depth of its services and initiatives.
Enhance Internal Efficiency Through Technology	Improve internal operational efficiency by leveraging technology, allowing CGDS to focus on delivering broader, more impactful services to the CGD community.	By improving internal efficiency with the adoption of advanced technology, CGDS will optimise operations, allowing more resources to be dedicated to creating meaningful, measurable impacts for the CGD community, ultimately enhancing service delivery and outcomes.

Achieving our Strategic Aims

Advocate for the CGD community		
Driver	Aim	Impact
Strengthen Strategic Partnerships in the Rare Diseases Community	Expand collaborations with rare disease charities to coordinate efforts, enhance advocacy, and increase awareness of CGD and other rare diseases.	By expanding collaborations with rare disease charities, we will amplify advocacy efforts, increase public awareness, and drive coordinated action for CGD and other rare diseases.
Provide Financial and Strategic Support for Rare Disease Initiatives	Support the wider rare disease community through our grant programme, in partnership with J4Gs, to provide financial assistance and promote key awareness initiatives.	Through our grant programme with J4Gs, we will provide essential financial assistance and fund key initiatives that empower and support the wider rare disease community.
Build and Strengthen Clinical Partnerships	Establish and enhance partnerships with the NHS, pharmaceutical companies, and clinical agencies to advocate for CGD and influence research, treatment, and policy.	By forging strong partnerships with the NHS, pharmaceutical companies, and clinical agencies, we will drive advancements in CGD research, treatment options, and policy decisions.
Empower the CGD Community through Storytelling and Advocacy	Mobilise individuals affected by CGD to share lived experiences, fostering greater public and medical understanding of the condition.	By mobilising individuals affected by CGD to share their stories, we will deepen public and medical understanding, fostering a more informed and empathetic healthcare environment.
Expand Membership and Community Engagement	Grow our membership base both within the UK and international throughout the strategy's lifecycle, reaching broader communities and ensuring improved access to CGD-related information and support	By growing our membership base, we will connect with broader communities, ensuring more individuals have access to vital CGD-related information, resources, and support networks. Become a portal to coordinate international and UK based CGD community.

Chronic Granulomatous Disorder Society

Strategy 2025 -2028

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