2023 - 2027
STRATEGIC PLAN

OUR MISSION
Our mission is to empower families and individuals living with rare NR2F1 gene variants through education, advocacy, and research.

OUR VISION
Our vision is that every single family and individual living with NR2F1-neurodevelopmental disorder will live a full and empowered life.
Dear Friends,

On behalf of the NR2F1 Board of Directors, it is my pleasure to present you with our 2023 – 2027 Strategic Plan. This plan outlines our strategic vision for the next five years as we work towards our mission of empowering families and individuals living with rare NR2F1 gene variants through education, advocacy, and research.

The NR2F1 Foundation was established in 2018 by six parents of children diagnosed with rare NR2F1 variants that cause a neurodevelopmental disorder called Bosch-Boonstra-Schaaf Optic Atrophy Syndrome (BBSOAS). Since then, our board of directors has doubled in size and serves more than 200 diagnosed families around the world, with the ambition to ensure that no family who receives a diagnosis feels lost or alone. Over the past five years, we have grown quickly, and now is the right time to formally plan for future success in order to best serve our community.

With that in mind, we have created our first strategic plan. In this document, we aim to clearly articulate what the organization stands for, what our goals for the future are, and to hold ourselves accountable by measuring and communicating our progress.

We are excited to serve you, our community, and ultimately, learn more about BBSOAS to give all those impacted, the brightest future possible.

Warm Regards,
Carlie Monnier
Co-Founder, NR2F1 Foundation
The NR2F1 Foundation was co-founded in 2018 by parents passionate about advocating for and increasing knowledge about Bosch-Boonstra-Schaaf Optic Atrophy Syndrome (BBSOAS), caused by changes in the NR2F1 gene. Our mission is to empower families and individuals living with rare NR2F1 variants through education, advocacy, and research. We focus on support / information for BBSOAS families and furthering BBSOAS / NR2F1 gene research.

BBSOAS, also known as Bosch-Boonstra-Schaaf Optic Atrophy Syndrome, is a rare neurological disorder caused by a disruption in the NR2F1 gene. BBSOAS is characterized by a wide array of clinical features, but the most common are vision impairment caused by optic atrophy, developmental delay, and intellectual disability. There are currently a few hundred known cases of BBSOAS worldwide with diagnoses rapidly increasing every month.
The NR2F1's strategic vision for 2023 - 2027 consists of three strategic objectives or "pillars". These pillars were identified through an organizational assessment in late-2022 and a through a two-day strategic planning meeting in early-2023. These pillars will help to guide our organizational priorities over the next five years.

**OUR STRATEGIC OBJECTIVES**

**EDUCATION**

**ADVOCACY**

**RESEARCH**

For each pillar, key measureable goals have been defined. The NR2F1 Foundation's Board of Directors will define priorities and activities to achieve these goals and report progress on an annual basis.
The NR2F1 Foundation has been a pioneer in providing information about BBSOAS / the NR2F1 gene since its inception. Education about the disorder remains an ongoing commitment and priority to our community.

**KEY GOALS:**

1. Provide understandable and accessible resources about BBSOAS / NR2F1 to multiple stakeholders

2. Bring together existing published literature on BBSOAS / NR2F1 into a central repository on the NR2F1 website

3. Grow the NR2F1 Educational Conference by 20% every two years and be bold in our efforts to engage more families
It is estimated that BBSOAS affects 1 out of every 250,000 babies born each year. This means that approximately 4,000 babies are born annually with a change in their NR2F1 gene around the world. As the number of BBSOAS cases increases annually through better awareness and identification of the disorder, we believe it is our responsibility to connect with, engage, and empower NR2F1 families across the globe.

**KEY GOALS:**

1. Support & engage individuals with BBSOAS and their families across the globe through the delivery of four virtual parent support groups every year.

2. Represent the NR2F1 community to external parties to help raise awareness of BBSOAS and accelerate research.

The NR2F1 Foundation is leading the charge to increase research in BBSOAS / NR2F1. We do this through community engagement, data collection, partnerships, awareness, and funding basic and translational science. We will continue to accelerate BBSOAS research over the next five years in the following ways:

**KEY GOALS:**

1. Empower and engage families in research through collaborative projects including the NR2F1 patient registry

2. Strengthen relationships with existing partners invested in research for NR2F1 while building new, powerful collaborations

3. Engage the scientific advisory board and external researchers to build a research strategy
NR2F1 Foundation understands that in order to meet our strategic goals, it is critical that we set ourselves up for long-term success. The following four categories reflect our sustainability initiatives to help us achieve our goals.

**KEY SUSTAINABILITY CATEGORIES:**

1. Develop a succession plan to ensure the organization transitions smoothly and without disruption in the event of leadership or organizational changes.

2. Diversify funding and revenue streams to ensure that the Foundation is financially stable for years to come.

3. Organize and develop the systems, processes, and procedures necessary for keeping the organization running smoothly and communicating efficiently.

4. Increase engagement with the community while creating new opportunities for community members to become more involved with the organization.
Over the next five years, NR2F1 Foundation will hold ourselves accountable for the strategy and key measurable goals we’ve laid out. We will provide annual progress reports to you, our community, to update you on the progress of our strategic objectives.

**KEY RESULTS INCLUDE:**

- **EDUCATION**
  - Continually develop and update easy-to-understand educational materials for various community partners and stakeholders.
  - Create a repository of publications and scientific literature that lives on the NR2F1 Foundation website and is easily accessible to all.
  - Be ambitious and bold in our efforts to increase attendance at the NR2F1 Conference every two years by meeting a 20% growth metric per conference.

- **ADVOCACY**
  - Establish, promote, and execute four virtual patient / caregiver meetings annually to keep the community informed on NR2F1 Foundation activities and research while offering support and empowerment to families across the globe.
  - Continue to represent NR2F1 by way of professional conferences, strategic alliances, and other partnerships in an effort to increase awareness of BBSOAS and the NR2F1 Foundation.

- **RESEARCH**
  - Increase enrollment in the NR2F1 patient registry and natural history study while keeping those enrolled engaged in current and future research projects.
  - Strengthen and increase the number of strategic relationships NR2F1 Foundation has with key thought leaders and researchers in BBSOAS.
  - Begin to build a research strategy through the engagement of researchers in BBSOAS and the NR2F1 gene.
The mission of the NR2F1 Foundation is to empower families and individuals living with rare NR2F1 gene variants through education, advocacy, and research. We invite you to get involved with the NR2F1 Foundation to help us advance our mission and contribute to the success of this five-year strategic plan.