for a better
tomorrow

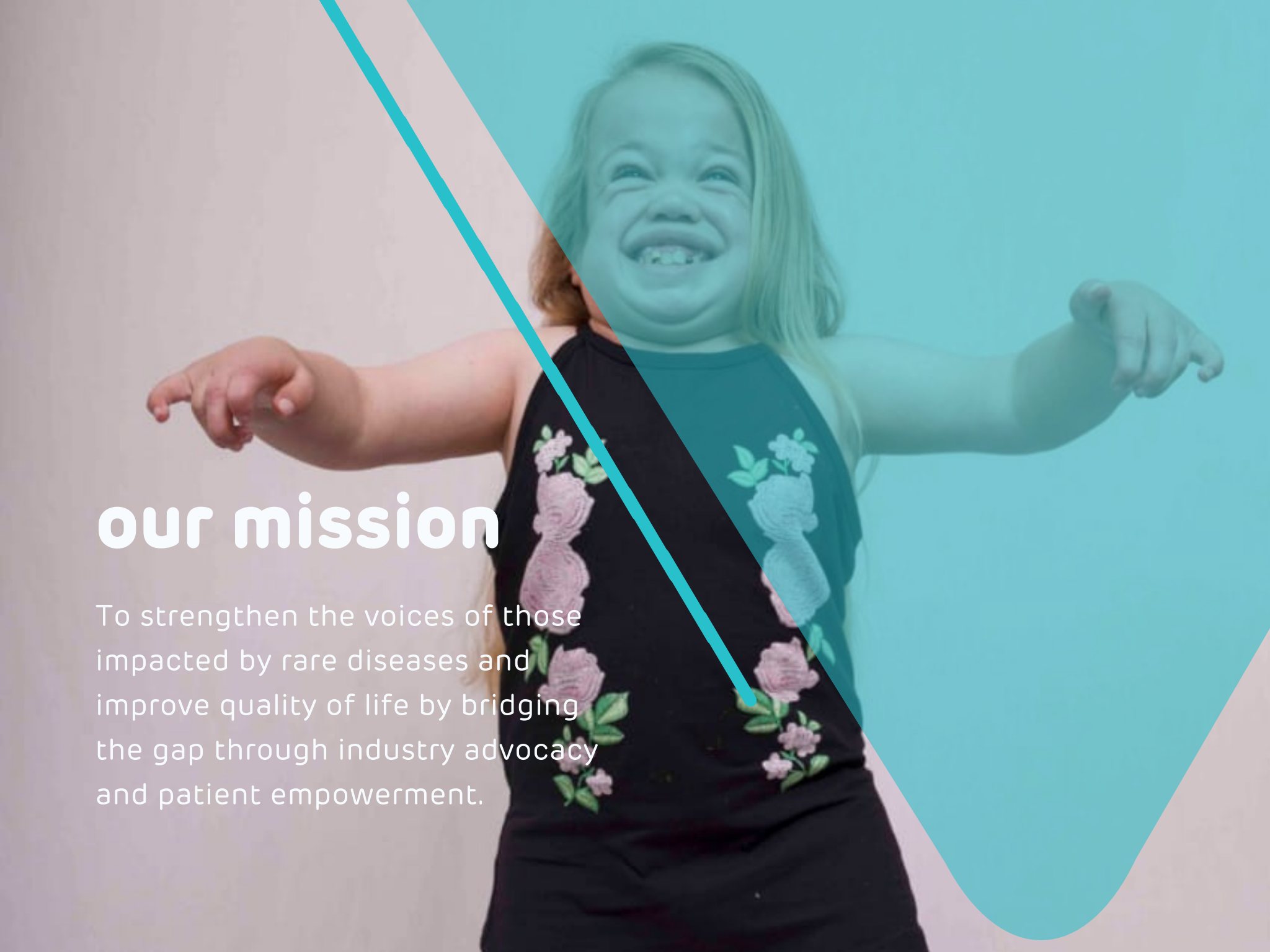
RARE DISEASES SOUTH AFRICA NPC COMPANY PROFILE

NPO 120 - 991 / NPC 2016/071131/08

Rare Diseases South Africa

Health cannot be a question of income; it is a fundamental human right

NELSON MANDELA



our mission

To strengthen the voices of those impacted by rare diseases and improve quality of life by bridging the gap through industry advocacy and patient empowerment.

our vision

A South Africa where those impacted by Rare Diseases access life-saving treatment and supportive care for improved quality of life.

about us

Rare Diseases South Africa (RDSA) works to ensure that people living with rare diseases (RD) and congenital disorders (CD) experience better recognition and support, improved health services, and a better life overall.

RDSA's vision is a South Africa where those impacted by rare diseases and congenital disorders can access life-saving treatment and supportive care for improved quality of life. This requires advocacy, support for research and medicine development, facilitating networking amongst patient groups and caregivers, raising general awareness with key stakeholders and the broader community, and providing a platform for key discussions around inclusive healthcare.

the journey so far

Since formal inception in 2013, RDSA has launched initiatives that have impacted the lives of over 1300 patients, continuously engaging with various governmental departments and organs of state, industry players and strategic stakeholders to raise awareness and move rare disease policy forward. In April 2020, Genetic Alliance South Africa (GA-SA), an affiliate member of ICBDSR since September 2019, was integrated into RDSA, adding congenital disorders to the rare disease mandate and research as a 4th strategic pillar, together with Advocacy, Patient Navigation and Community Engagement.

the numbers are important

A key focus of RDSA research is developing an evidence-base as a foundation for advocacy efforts to improve genetic services countrywide. With national surveillance of birth defects underreporting by over 90% (Lebese at al 2016), and no surveillance of rare diseases, there is an urgent need to set up relevant systems to develop robust patient registries and improved surveillance

what we do

our strategic focus

ADVOCACY

Represent patients affected by rare diseases with regards to policy, healthcare costs and delivery.

NAVIGATION

Guide patients from presentation of symptoms, through to end of life care - through and around barriers in the complex healthcare system - to help ensure timely diagnosis and treatment.

ENGAGEMENT

Ensure patients feel better supported throughout their journey by creating awareness and platforms in which our community can connect and support one another.

RESEARCH

Focuses on key, patient centric issues relevant to the local and global rare disease and congenital disorder communities.

advocacy

RDSA aims to represent patients affected by rare diseases with regards to policy, healthcare costs and delivery.

RDSA provides services to patients, and those supporting them, who are navigating the complex healthcare system. We work directly with patients to ensure they have a voice in their care and have access to information to promote informed decision making.

Our Advocacy programmes include the following key areas:

- Create a united voice in the rare disease community
- Contribute and participate in policy development and service delivery
- Monitor service delivery relating to rare diseases
- Facilitate development and maintenance of patient registries
- Incorporate principles as Rare Disease patient charter in advocacy efforts

advocacy

navigation

Patient Navigation is the process by which we guide patients from presentation of symptoms, through to end-of-life care - through and around barriers in the complex healthcare system - to help ensure timely diagnosis and treatment.

Rare Assist was developed with the aim of assisting rare disease patients with obtaining access to treatment and services. The project ensures that patients receive appropriate support from presentation of symptoms through to end-of-life care.

Programme elements include:

- case management
- psychosocial support
- genetic counselling
- multi disciplinary referrals

navigation

community engagement

Community Engagement is an important and necessary channel within the rare disease community to ensure patients feel better supported throughout their journey. Feelings of isolation and abandonment are synonymous with rare diseases and congenital disorders, and RDSA aims to overcome this by creating awareness and platforms in which our community can connect and support one another

community engagement

Programme includes

- (R)aising (A)wareness through (R)ecreational (E)vents ACTIVists
- Webinar Wednesdays
- RareX Bi-Annual conference
- Rare Disease Day (National Partner)
- Creating awareness about Rare public awareness series
- Denim Walk

research

RDSA research focuses on key, patient centric issues relevant to the local and global rare disease and congenital disorder communities. Targeted projects provide an evidenced-based foundation for our advocacy work, connect researchers and patients, and highlight the lay expertise of those living with rare diseases and congenital disorders. Spearheaded by Dr Helen Malherbe, RDSA underpins the RDSA advocacy efforts.

research

Current research projects

- Epidemiology of rare diseases and congenital disorders
- Definitions and Terminology
- Rare Diseases Research Database
- Research Forum development

sustainability

As a non-profit organisation, RDSA implements a comprehensive financial sustainability strategy. Our various programmes provide funding/sponsorship opportunities to diversify our funding income. Our annual budget includes income from events, corporate sponsors and funders, programme-specific funding, research grants, international and small/ medium business donors. A strategic, three-year campaign focused on increasing our small donor portfolio income by at least 30% was implemented in 2020 and aims to increase our financial reserves through unrestricted funding, which is supplemented by our annual awareness and income generating events/ campaigns, such as Rare Diseases Day.

our people

RDSA leadership is headed by our CEO and Founder, Kelly du Plessis. Her expertise in the field of rare diseases has seen her present at various national and international conferences and she was awarded the African Leadership Award for Healthcare in 2016. She is guided and supported by a collectively experienced Board which includes members with congenital, medical, pharmaceutical, marketing, research, and entrepreneurial expertise to ensure strategic directive, effective partnership development, stakeholder engagement and effective succession planning in organisational development.

building capacity

RDSA staff include experts within the various departments of operations. Continued training and capacity building forms part of the key objectives of the organisation strategy. Partnerships with industry networks, advocacy leaders, government department and pharmaceutical companies provide continued development opportunities for all staff and volunteers to attend seminars, workshops, conferences, and skills training events. Additional capacity through external consultants provides expert guidance and mentorship to ensure effective implementation of the organisational strategy. Mentorship and development are incorporated into programme activities to encourage a culture of learning within RDSA.

meet the team

yes, we are all woman :)

Kelly
ceo & advocacy

Helen
research

Nomsa
community manager

Shevaun
events & digital

Sharon
operations

Megan
admin & rare bears

Tash
brand manager

Jen
media partnerships

Mariley
fundraising

Carla
rare disease day project manager

"Do not follow where the path may lead. Go instead where there is no path and leave a trail."

-RALPH WALDO EMERSON

leadership

our governing board

What was initially envisioned as an all-encompassing support group for South Africans affected by rare conditions (or those who remain undiagnosed) has evolved into a formally registered NPO that is internationally recognised for its advocacy efforts. As a result, the management and oversight of the organisation has been formalised.

Each board member brings with them expertise and knowledge in various aspects of business as well as life-experience and personal understanding of rare diseases and their impact on patients, families, stakeholders, and society at large.

Kelly du Plessis

mom. advocate. leader. fan of motorsports

Kelly du Plessis is the CEO & Founder of Rare Diseases South Africa which was born out of necessity when her oldest child was diagnosed with Pompe Disease in 2011 at 11 months of age. Having dedicated her life and career to furthering the plight of those impacted by rare diseases in developing countries, Kelly serves on various boards and committees which focus on improving the quality of life for rare patients.

Career Highlights:

- Winning CEO of the Year: SA (2021) - Global CEO Excellence Awards
- Winning African Leadership Award - 2016
- Presenting at the United Nations Rare Disease Policy Event

Kelly has taken rare disease policy and patient advocacy to new heights in South Africa and has presented at various national and international conferences to raise awareness and create a new narrative in terms of treatment and access for rare patients. Kelly has been awarded various awards and accolades for her contribution to healthcare both locally and abroad.

Dr Helen Malherbe

mom. researcher. graph enthusiast.

Career Highlights:

- Completing PhD in 2017
- Working with Prof Bernadette Modell on modelling approaches to quantify the burden of CDs
- Involvement in international (WHO committees) on birth defects and being a key author on the national human genetic guidelines (policy development) for the country

Helen became part of the rare disease community in 2004 when she lost her first child, Madeleine, to Trisomy 18 (Edwards Syndrome), and soon after established a contact point for families in South Africa affected by the same condition. In 2017, Helen completed a PhD to investigate the renewed need for the care and prevention of congenital disorders in South Africa, from which 13 scientific articles have been published to date.

Helen was Honorary Chair of Genetic Alliance South Africa (GA-SA), a non-profit, membership organisation uniting stakeholders relevant to the care and prevention of congenital disorders (CDs) until April 2020 when GASA was integrated into RDSA. Helen was appointed as an honorary RDSA Director overseeing Research and Epidemiology.

Nikki Melles

digital marketer. brand custodian.
adventure seeker. rugby fanatic.

Career Highlights:

- Being a founding member of Rare Disease South Africa
- Landing the role of Head of Media at Byte - encouraging me to spread my wings overseas in the UK.

Nikki is a passionate digital media specialist with both her undergraduate and postgraduate degrees in marketing. She currently heads up a paid media department at one of the fastest growing agencies in Europe and has used her knowledge of brands and media to assist in building and developing RDSA over the years.

She is one of the founding members of RDSA and has been strategically involved in the growth, evolution and transformation, not only of the organisation, but also the lives of those living in South Africa with rare conditions.

Nicole Austin

mom. functional pharmacist. activist. mountaineer.

Career Highlights:

- Surviving 39 days on an island as Runner up in survivor season 7
- Being crowned Mrs South Africa in 2017
- Many successful Mountain climbs around the world, including to the highest point in SA, with groups of adventurers.

TV presenter, CEO, and Adventurer are just some of the impressive titles associated with Nicole Austin. She is the Survivor SA Season 7 runner-up, Mrs South Africa 2018, a qualified pharmacist, a serial entrepreneur and mom to a Rare warrior after her daughter was diagnosed with a life-limiting rare disease, Cystic Fibrosis, at just 6 weeks of age.

With a passion for health and preventative medicine, Nicole uses her mobility and fitness to raise awareness for those without full health, by participating in mountain climbs, sporting events and outdoor adventures all over the world – with her intention to liberate courage in others to do the same

Roxy Burger

mom. content producer.
entrepreneur. lover of fashion

Career Highlights:

- Working on international channels like MTV and E! Entertainment
- Playing Survivor and lasting way longer than anyone thought I would
- Creating and establishing the first fully fledged luxury piercing boutique in SA

At the age of just 32, Roxy Burger has achieved what many fail to do in a lifetime. Having graduated with a Bachelor Degree in Audio-visual Production Management, Roxy is as talented behind the camera as she is in front of it and is an avid producer, presenter, radio DJ and reality show participant. She too, is the mom of a rare warrior and utilises her reputation and following to advocate and create awareness of rare diseases.

With a broadcasting career spanning two decaded, Roxy brings with her a wealth of knowledge on media engagement and story-telling, as well as entrepreneurual flair.

company details

NPO

Non-Profit Organisation (NPO) registered with the South Africa Department of Social Development (NPO 120-99)

PBO

Public Benefit Organisation (PBO) registered with the South African Revenue Services (SARS) (PBO 930060119).

NPC

Non-Profit Company (NPC 2016/071131/08) registered with the Companies and Intellectual Property Commission (CIPC)

BEE

Rare Diseases SA has 100% BBB-EE Social Development Recognition

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Rare Diseases South Africa