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RARE
DISEASES



WE ARE RARE

Rare Diseases South Africa is a registered Non-Profit Organization assisting all patients impacted by rare diseases to access life-saving treatment and supportive care for improved quality of life.

Established in 2013 by Kelly du Plessis from personal need on the diagnosis of her son with Pompe disease.

RDSA provides support, patient advocacy and a network to rare disease patients in South Africa.

OUR KEY OBJECTIVES

Patient navigation

Ensure a challenge-free, supported journey from presentation of symptoms to end-of-life for patients affected by rare diseases.

Advocacy and expanding access

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

Community Engagement

Collaborate with civil society to ensure greater awareness and networking platforms for rare diseases in South Africa.

OUR VISION

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

OUR MISSION

To advocate and facilitate engagement between those with the ability to prevent, intervene, treat and provide supportive care for those impacted by rare diseases.

RARE BEAR PROJECT

A community project with KyaKids, creating employment for the ladies of Kya Sands whilst creating joyful companions for our patients.

For our 2nd birthday, we decided that we wanted to commission bears for our paediatric patients so that they could have a friend that was all theirs to be with them through their journeys of survival.

BUT, we didn't want perfect bears, or for our bears to be the same. We wanted BEARS that were RARE. So, we engaged with our friends at KyaKids, a community project run by the Bryanston Bible Church, which upskills woman of the community. Together, we have trained the ladies to crochet, and now our project has 54 ladies employed full-time making rare bears. Rare Bears are available for purchase or donation via our online store.

PATI ENT SUP PORT

RARE CARE PACKS

#RareCare packs are delivered to patients in hospitals who are there for unexpected admissions. This forms part of our Mandela Day initiatives.

Over **7000**
rare diseases considered rare



Globally, over
350mill
people affected with
a rare diseases

50% of rare diseases affect children



30% of children with a rare disease won't reach their 5th birthday



Over
95%
of rare diseases do not have 1 single FDA approved drug

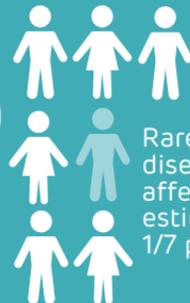
Rare diseases are responsible for
35% of deaths in the first year of life



RDSA started with 0 employees and has grown to **7** employees over 4 years

An estimated
3.7
million people affected with a rare disease in South Africa based on modelled data, and global prevalence

RDSA has impacted the lives of OVER
5000
patients during our existence



Rare diseases affect an estimated 1/7 people

Has raised over
R1mill
in funds since 2013 towards our projects and programmes



RARE

A C T I V I S T S

Our rare activist programme is aimed at all those wanting to assist us in raising funds and awareness for our cause, our patients and ultimately the rare disease community.

Be it volunteering at an event, hosting a family day, or partaking in one of our many sporting teams and using your mobility for the advantage of others, there is a always a way for you to get involved as a Rare ACTIVist.

Sign up as a volunteer, list your skills and the area you reside in, and we will get in touch when we are having events in your area

Use your mobility to the benefit of others, by running, swimming or cycling for us.

#Run4Rare #Swim4Sadie #Ride4Rare

OUR FUT URE

We have strong plans for the future.

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WHAT DO WE NEED TO SUCCEED?

HOW YOU CAN HELP US

1. Sign up to be a Rare ACTIVist
2. Volunteer your time and skills
3. Donate funds via:

EFT/Direct Deposit
Banking Details:
Rare Diseases South Africa
First National Bank
Branch: Sunninghill
Branch Code: 251655
Acc No: 624 11658 034
Ref: Your name/ email

Zapper app



Our online store;
visit our website at

www.rarediseases.co.za

Patient navigation

- Develop clinical guidelines and referral pathways for identified rare diseases in south africa.
- Develop patient information/ educational material relating to; Disease, Treatment and Supportive services
- Provide referral services for both treatment and support to patients with rare diseases.

Advocacy and expanding access

- Create a united voice in the rare disease community.
- Contribute and participate in policy development and service delivery
- Facilitate development and maintenance of patient registries
- Implement the patient charter for Rare Diseases in SA (Available at www.rarediseases.co.za)

Community Engagement

- Create awareness events and campaigns relating to rare diseases
- Develop and participate in civil society alliances with linkages to the rare disease patient journey