Rare Diseases South Africa

RDI Meeting
Spain, June 2017
• NPO and PBO assisting all patients impacted by a rare disease
• Has impacted the lives of OVER 5000 patients
• Raised over R1million in funds since 2013 which have gone to project initiatives and patient support
• Growing year on year!

BACKGROUND ON RDSA
RDSA IN NUMBERS

Members

Patients: 959
Caregivers: 160
Support groups: 191
Healthcare professionals: 1211
ACTIVists: 353
Diseases: 602

Community Engagement

Facebook Fans: 41853
Twitter followers: 3068
Email list: 8500
Online Support Groups: 7
WhatsApp patient groups: 11
DEFINING RARE DISEASES IN SOUTH AFRICA
DEFINING RARE DISEASES IN SA

- Estimated 3.7 million people affected with a rare disease
- No local definition available for Rare Diseases in SA
- A comprehensive legislative and regulatory framework exists however, implementation has been fragmented and unsustained
CHALLENGES FOR RARE DISEASES IN SA

- The need for a definitive definition of a “rare disease”
- The need for big data in terms of the threat of rare diseases in South Africa, patient numbers and treatment outcomes
- Guidelines and Clinical protocols are required for the effective treatment and management of rare diseases
- Rare diseases are underdiagnosed and underfunded in South Africa and existing resources are not employed to ensure maximum return on investment, efficiency or efficacy
- No existing culture of collaboration between stakeholders – focus of support groups is very singular and disease specific
GENERAL HEALTHCARE CHALLENGES FACED
GENERAL HEALTHCARE CHALLENGES

- Limited Financial resources regarding individual patient advocacy
- Culture of apathy amongst South African healthcare consumers
- Cultural, class, literacy diversity of South Africa
- Patients lack of understanding on entitlement to rights
- Accessibility of information
- Escalation processes are cumbersome and ineffective
- Supportive care is often the only possible intervention and is often not recognized as a medical need
- Treatment decisions are based on cost alone
- Poor lead times from diagnosis to treatment, inaccurate diagnosis, unregistered treatments continue to minimize access for patients
WHAT IS RDSA DOING TO ADDRESS THESE CHALLENGES

Our objectives & plans include:

• Patient navigation: supported journey from presentation of symptoms to end-of-life for patients affected
• Advocacy and expanding access - with regards to policy, healthcare costs and delivery.
• Community Engagement- to ensure greater awareness and networking platforms for rare diseases in South Africa.
KEY OBJECTIVE: Patient navigation

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

1. Develop clinical guidelines and referral pathways for identified rare diseases in South Africa
2. Provide referral services for both treatment and support to patients with rare diseases
3. Develop patient information/ educational material relating to;
   - Disease
   - Treatment
   - Supportive services
4. Provide case management services for patients requiring treatment
5. Provide tools and resource material to improve patient journey
KEY OBJECTIVE: Advocacy & expanding access

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

1. Create a united voice in the rare disease community.
2. Contribute and participate in policy development and service delivery
3. Monitor service delivery relating to rare diseases
4. Facilitate development and maintenance of patient registries
5. Civil society: incorporate principles as rare disease patient charter in advocacy efforts
KEY OBJECTIVE: Community Engagement

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

1. Create awareness events and campaigns relating to rare diseases.
2. Develop and distribute educational material and campaigns for the public and targeted stakeholders.
3. Develop and participate in civil society alliances with linkages to the rare disease patient journey.
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