



# TOOL FUNDRAISING AND EVENTS KIT

**RARE**  
ACTIVISTS

 **Rare  
Diseases**  
South Africa

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Thank you for giving your time and efforts to fundraise for RDSA. By fundraising, you play a leading role in providing help and inspiring hope to those affected by rare diseases.

With the funds you raise, you will make it possible to further our aim of **empowering patients through navigation, advocacy and engagement.**

For over 5 years, RDSA has used its programs to support those impacted by rare diseases across South Africa.

As a result of increased awareness, improved diagnostics and quicker access to appropriate treatment and supportive care, the quality of life of these patients with rare conditions has significantly increased.

The improved landscape reflects the dedication and support of our donors, fundraisers, corporate sponsors, stakeholders, and most importantly, our patients.

Rare Diseases South Africa is:

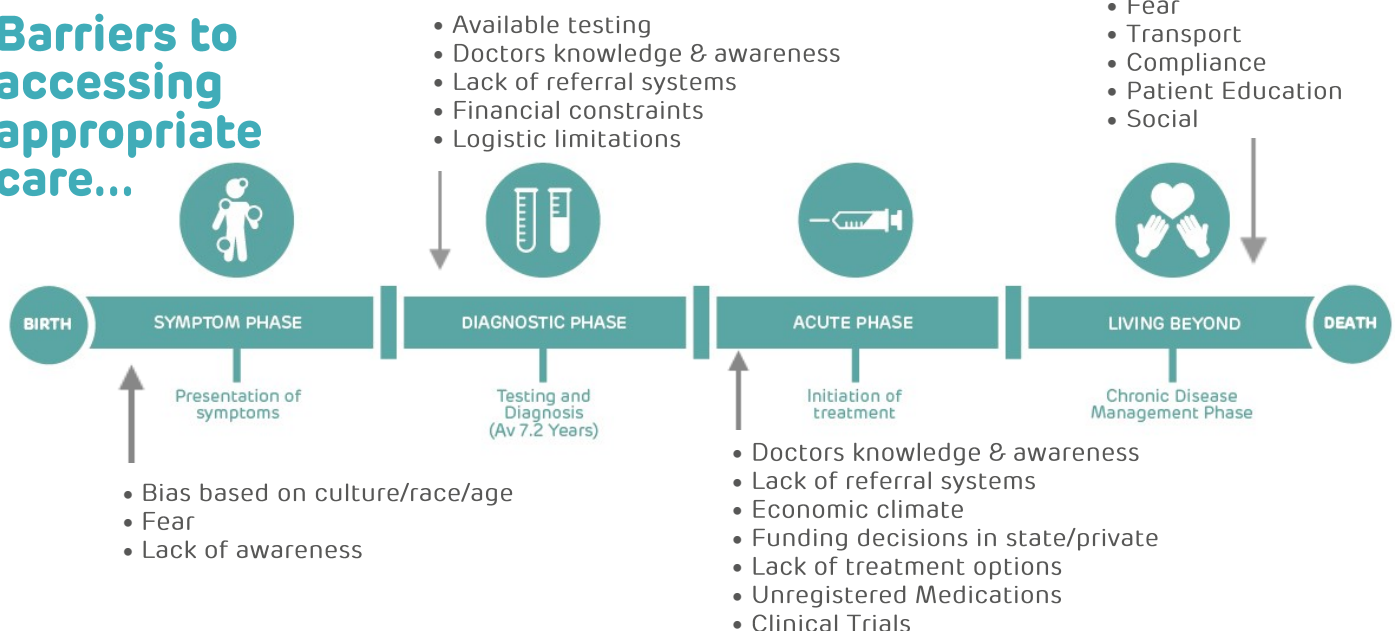
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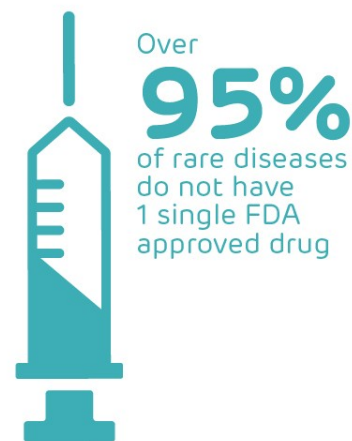
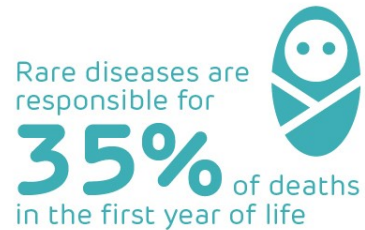
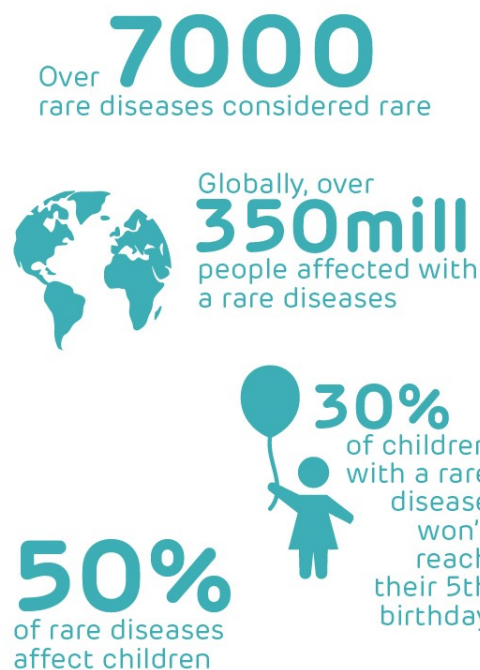
## Barriers to accessing appropriate care...





## Know The Facts About Rare Diseases

GLOBAL STATS



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



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

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



Rare diseases affect an estimated 1/7 people

LOCAL STATS



## GET INVOLVED WAYS YOU CAN HELP US

**USE YOUR MOBILITY  
TO BENEFIT OTHERS**  
by becoming a  
Rare ACTIVist  
activists@rarediseases.co.za

**1. EFT/DIRECT DEPOSIT**  
Banking Details:  
Rare Diseases South Africa  
First National Bank  
Branch: Sunninghill  
Branch Code: 251655  
Acc No: 624 11658 034  
Ref: Your email

**3. MONTHLY DEBIT  
ORDER** Email  
admin@rarediseases.co.za

### DONATE

There are a few ways  
you can make a  
monetary contribution:



**2. ZAPPER  
APP**

**4. GIVEN GAIN**  
www.givengain.com/  
c/rarediseasesa/

**5. ON OUR  
ONLINE STORE**  
www.rarediseases.co.za

**VOLUNTEER**  
your time and skills  
www.rarediseases.co.za/volunteers



I am a proud mother of a #RareWarrior. I would like to help create awareness for rare diseases. If I look at how strong our little miracle is, I want to fight hard for her to have the best possible future. She is my inspiration.

**Madelein de Wet,**  
mom to rare warrior Amore

## What is a Rare ACTIVist?

Each year, hundreds of people across the country run, swim, ride, host and volunteer at events giving their time, energy, and resources to help RDSA.

**Rare ACTIVists are people who are passionate about using their mobility to help those impacted by rare diseases.**

## How to become a RARE ACTIVist



**Step 1**  
Choose your  
campaign



**Step 2**  
Fundraise  
and donate



**Step 3**  
Share your  
campaign



## #Ride4Rare

A cycling initiative for RDSA, which allows members of the public to raise awareness and funds for rare disease patients, using cycling events as a platform.

**Events: JUMA, Telkom 947 Cycle Challenge, Cape Town Cycle Tour**

## #Swim4Sadie

In loving memory of Sadie Penn, Swim4Sadie aims to raise the profile of rare conditions as well as create a platform for fundraising to assist families affected by rare diseases using swimming as the main focus.

**Events: Midmar Mile, Sun City Swim, MadSwimmer Endurance Events**



## #Run4Rare

Running/walking initiative for RDSA, which allows members of the public to raise awareness and funds for rare disease patients, using walking/running events as a platform.

**Events: JURA, Old Mutual Two Oceans Marathon, MTN Walk The Talk with 702, Walk the Paws, Denim Walk**



## #Raise4Rare

Host a fundraising event which benefits RDSA, and help us achieve our objectives.

**Events:** Rare Disease Day, Golf Days, School Events, High Tea's, Birthday Pledges, Concerts

## #Care4Rare

RDSA often needs assistance at our events and family days, as well as with markets, patient projects and administrative tasks.

**Events:** Sporting events, family days, hospital visits, patient assistance, administration tasks



**"The best way to find yourself, is to lose yourself in the service of others."**

**- Ghandi**



### RDSA Events

The level to which RDSA is actively involved in your event will depend on the nature of the event you wish to host. Please refer to the table below outlining what support RDSA can offer.

Level 1	Level 2	Level 3
<p>I.e: Personal Fundraisers / General Events (Event benefits an individual)</p> <ul style="list-style-type: none"> <li>• Use of RDSA logo</li> <li>• Inclusion of event on RDSA website</li> <li>• Inclusion of event on social media and relative communication platforms.</li> </ul>	<p>I.e: Disease symposiums / community / fundraisers / events (Event benefits a group of patients / community)</p> <ul style="list-style-type: none"> <li>• Level 1 Benefits +</li> <li>• RDSA representatives included in programme / organizing committee</li> <li>• RDSA speakers at events</li> <li>• Satellite sessions</li> <li>• No financial commitment from RDSA</li> </ul>	<p>I.e: Conferences/ Symposiums / Forums (Event benefits RDSA objectives)</p> <ul style="list-style-type: none"> <li>• Level 2 Benefits +</li> <li>• Financial support from RDSA</li> <li>• RDSA support in terms of bursaries</li> <li>• Foster knowledge / skills transfers</li> </ul>

# RARE ACTIVist FUNdraising Rewards Programme

To not only motivate, but also thank all our Rare ACTIVists who continually raise funds for Rare Diseases South Africa, by running, swimming, cycling or hosting events on our behalf, we have implemented a tiered rewards programme.

Link your GivenGain fundraising project to our Rare ACTIVists Rewards campaign, so we can start tracking your progress.

[www.givengain.com/cc/rareactivist/](http://www.givengain.com/cc/rareactivist/)



# Top 7 Things To Do Before You Fundraise

## 1. Choose your time

Make sure to give yourself enough time to plan, prepare, and ask for donations. We recommend timelines that are no more than 3 months before your actual fundraiser, and no less than 2 weeks. This creates more urgency for people to give to your fundraiser when you ask friends and family for support.

## 2. Set a Goal

R50 pays for a patient's transport to hospital, R120 donates a rare bear. It is helpful to set a goal based around what your donations can do. Setting a goal also gives you a built-in reason to update your audience and follow-up with them after they have donated.

## 3. Choose a Name

In choosing a name for your fundraiser, we always suggest including the word "rare". Please represent RDSA's patients with pride, and refrain from using terms like "rare disease sufferers".

## 4. Approve All Collateral

All printed materials (flyers, t-shirts, banners, etc.) for your fundraiser with the RDSA name or logo must be approved by RDSA's Marketing team prior to distribution. All drafts should be submitted to [design@rarediseases.co.za](mailto:design@rarediseases.co.za)

## 5. Prepare necessary admin

As a fundraiser or fundraising group hosting an event, there may be paperwork that needs seeing to, insurance and permits required by law (e.g. insurance, JOC applications etc). If there is anything you require assistance with, please contact [support@rarediseases.co.za](mailto:support@rarediseases.co.za)

## 6. Be Reputable

RDSA reserves the right to decline association with any event or organization for any reason, including its belief that such an association may have a negative effect on the credibility and/or reputation of RDSA. Please do not post any nudity or graphic content on your fundraising page.

## 7. Gather branding

RDSA can provide you with flyers and brochures for your fundraiser. These are great materials that you can use to help include and inform your donors. If you are looking for further items to represent RDSA with, check out our Online Store inspired apparel and accessories.



# Top 5 Things To Do During Your Fundraiser

## **1. Be the first to donate**

Inspire others to donate by making the first donation yourself. Make your donation the same amount you hope for your supporters to contribute. Encourage others to match this donation.

## **2. Share**

Get the word out on social media, e-mail, and personal phone calls. Ask your friends to help promote your event and invite everyone to join. Flyers, posters, Facebook posts, and tweets can help inform a wide audience in a very short amount of time. Tag us on social media so that we can see what you are doing, and raise awareness with you.

## **3. Ask**

Don't feel guilty about asking. You will find that people will be willing to be included in your fundraiser. Lots of people plan on donating, but simply forget due to your email getting buried in their inbox - follow up and encourage them to donate early.

## **4. Document Your Event**

Take pictures, videos, and get quotes from participants and donors. This is critical to ensuring that everyone feels involved in your fundraiser. Whether you are running a solo marathon or hosting a golf day, take pictures and share the journey of your event. Don't forget to send these to [events@rarediseases.co.za](mailto:events@rarediseases.co.za) after your event.

## **5. Transparency**

If you are donating a percentage of sales to RDSA, please ensure your audience knows your intentions. RDSA asks that you disclose to your sponsors and guests the amount in which their participation will impact RDSA, i.e. R10/ticket or 20% auction sales.

## Social Media Guide

One of the best ways to make your fundraiser successful is by sharing it with friends and family on social media. Whether you're hosting an event, managing a fundraising event, or participating in a race, sharing what you are doing and why you are doing it will help get others involved. Here are a few "Dos and Don'ts" to help you market your fundraiser successfully through social media:



### Do's

- Use the share buttons on your fundraising page
- Share inspiring and positive anecdotes
- Tag RDSA in your posts
- Use the hashtag #Care4Rare
- Tag your friends who have donated to say "thanks"



### Don't's

- Make duplicate posts on multiple walls
- Send @ replies with duplicate or unsolicited content
- Post any nudity or suggestive images
- Make every post an ask

**Mobilize your network:** as the saying goes, "1 plus 1 equals 11".

**Maximise the visibility of your project:** asking your network to campaign on your behalf and also spread the word about it!

## Facebook

Find us: [Rare Diseases South Africa](#)  
[Rare Activists](#)

- Create a Facebook event and select people to attend. This will be a great way to keep track of people interested in your event and relay any details to the attendees.
- Share your personal fundraising page. Include a link of where your supporters can go to make a donation.
- Relate to others by letting them know why you are fundraising for RDSA.
- Share your story!
- Thank donors by giving them a shout out.
- Tag us and our social media gurus will be sure to share the love in return!
- Use Hashtags #Care4Rare, #Ride4Rare, #Swim4Sadie #Run4Rare

Example: "An estimated 1 in 10 people are affected by a rare condition, making them individually rare but collectively common. Help me reach my goal of raising R2000 in my upcoming cycle race.  
#Care4Rare and donate now at <<<insert fundraising link>>>

## Twitter

Find us: [@RareDiseasesSA](#)  
[@RareActivists](#)

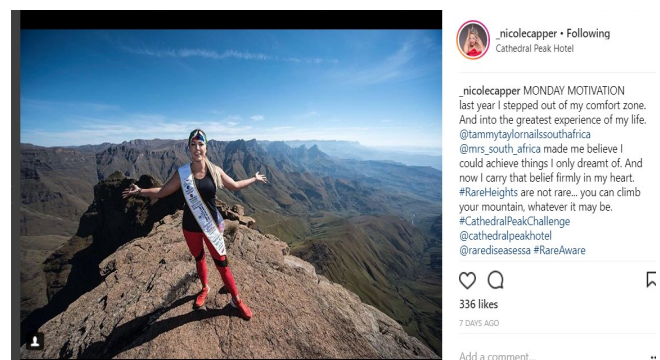
- Introduce your fundraiser to your followers; briefly explain why you are #Care4Rare
- Share a link to your personal fundraising page or a website where they can learn more about your event.
- Tweet before, during, and after your fundraiser. Let your supporters know how your planning is going, how far away you are from your goal, and recap after!
- Remember, include @RareDiseasesSA and hashtag #Care4Rare in your tweets- this way we can see all your great updates and encourage you too!

Example: ""We are halfway to our goal! Please share and keep the donations going!  
Visit (URL) to give and support @RareDiseasesSA in their mission to help  
Rare disease patients." #Care4Rare

## Instagram

Find us: [@rarediseasesa](#)

- Take LOTS of photos.
- Capture the memories you create as you carryout your fundraiser! We love to see all the fun and unique ways you are raising awareness and changing the world.
- Feel free to include a link to your fundraising page in your BIO—*remember that Instagram doesn't allow you to place a link in your post.*
- Tag us and you just might see your photos on our Instagram feed.
- Use Hashtags #Care4Rare #livingbeyond #Ride4Rare #Swim4Sadie #Run4Rare





# Things To Do After Your Campaign Has Ended

## **1. Submit your donations**

As a standard rule, donations are due no more than 30 days after your fundraiser, and the easiest way is via EFT. If you require any invoices, send an email to [support@rarediseases.co.za](mailto:support@rarediseases.co.za)

## **2. Send your donors a report**

No matter how big or small your fundraiser is, it's always important to let the people who made it all happen know about your success. Consider including some inspiring stories from patients survivors, or personal anecdotes that you have about rare diseases. Send donors and volunteers a thank-you note to tell them how important their contribution was to you, and in assisting RDSA empower patients. You can encourage others to "pass the baton" on and create their own fundraisers.

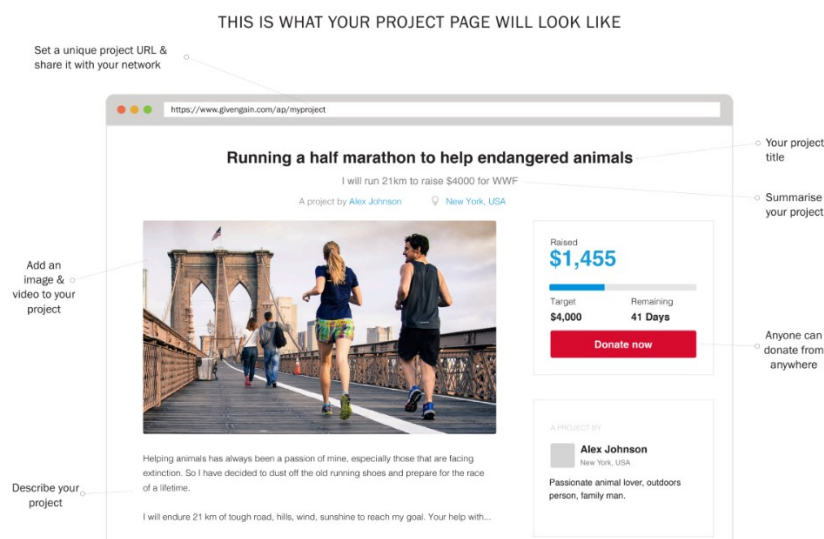
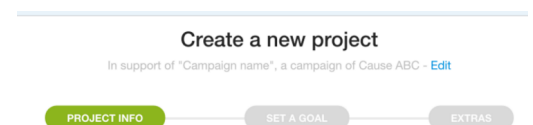
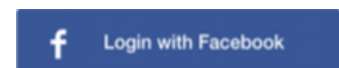
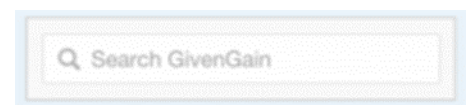
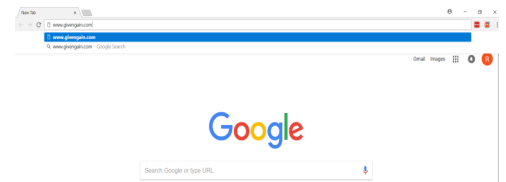
## **3. Request your Section 18A receipt**

As RDSA is a registered Public benefit organization, and contributions made to RDSA are section 18A approved. If you require a donation receipt for income tax purposes, please email [finance@rarediseases.co.za](mailto:finance@rarediseases.co.za) and include your full name, ID number, income tax number, physical address as well as the proof of payment for the donation requiring a certificate.

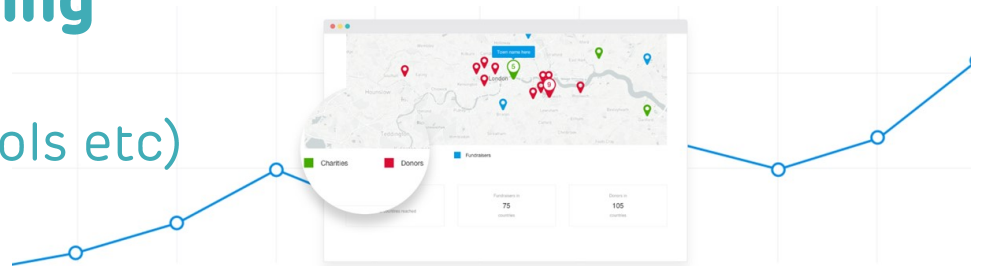
## **4. Start planning the next one...**

# For Individual Fundraising Campaigns, follow these 5 easy steps:

1. Go to [www.givengain.com](http://www.givengain.com)
2. In the search field on GivenGain, look for Rare Diseases South Africa
3. On the cause profile, select a campaign (Rare ACTivist Rewards), then click on the "Start fundraising" button.
4. If you do not have a GivenGain account yet you can easily register for a free activist account with your Facebook login details or an email address.
5. Complete the project steps. Remember to add a video, photo or both providing more information about your project. Set a realistic fundraising goal – you can always change it later. Any funds raised will go to the cause, even if you don't reach your goal.



# Team Fundraising Projects (companies, schools etc)



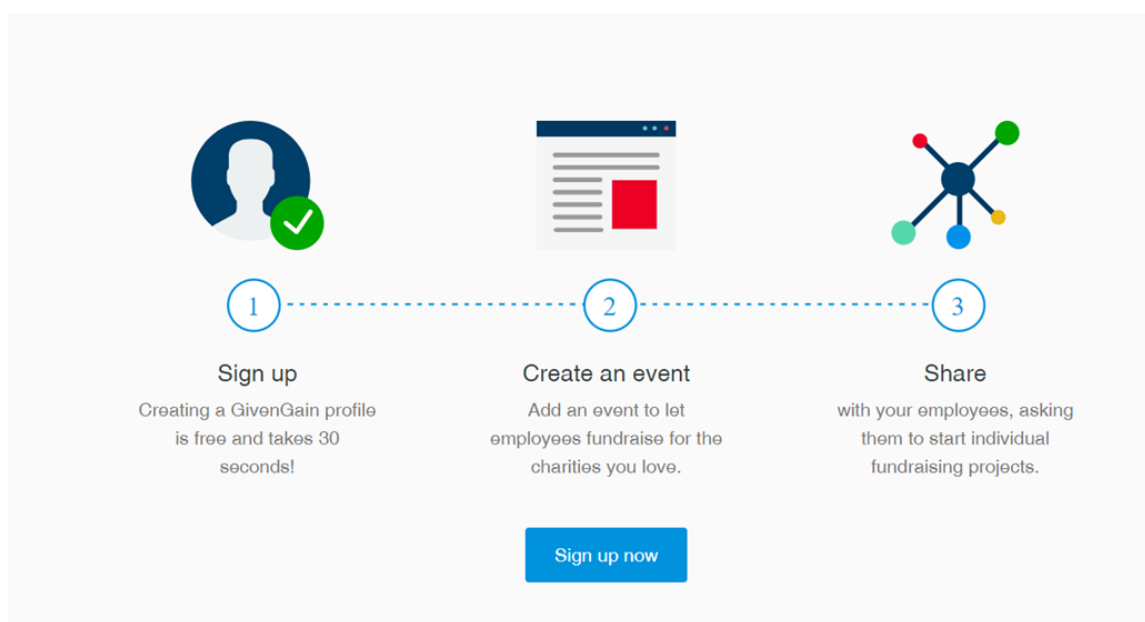
### What is GivenGain Teams?

GivenGain Teams enables groups (company employees, sporting event participants, clubs, families and friends, etc.) to fundraise together for charity. A Teams account provides a detailed overview of a Team's fundraising activities for a specific charity or charities during a fundraising event, and can include graphs, a leaderboard and more. This enables it to see the success of its online fundraising, identify the best individual fundraisers as well as the donor countries it has reached, and provides real-time feedback to stakeholders such as board members or the public.

### Who may apply for a Teams account on GivenGain?

Any group (company employees, sporting event participants, clubs, families and friends, etc.) may apply for a Teams account and create a fundraising event. Once the event has been created, a GivenGain charity (or multiple charities) can be linked to it, allowing the charity to receive donations via Team members' fundraising projects.

- Empower employees to fundraise together to maximise your social impact.
- Encourage friendly competition with leaderboards and fundraising challenges
- One place to track Teams' progress and impact
- Build a transparent CSI history with analytical reporting





## Frequently Asked Questions

### In-Kind Donations

**If a business donates goods or services for my event will they receive a tax receipt from NBCF?**

Non-cash gifts given directly to a fundraiser can be tax-deductible gifts to RDSA. The key is that the gift was given on behalf of RDSA for a fundraiser that is 100% for RDSA. The donor should present RDSA with a written document stating that 100% of the proceeds for project X was for the benefit of RDSA, and on behalf of RDSA, donor gave X items at X value each.

After we receive the document from the non-cash gift donor, we will provide them with a "thank you letter" that serves as a tax receipt. An example of what the document needs to say would be:

*"X gave 100 t-shirts to Z fundraiser on behalf of RDSA, at a value of R12 each. All net proceeds from Z fundraiser were for the benefit of RDSA."*

We will send our Section 18A determination letter for the companies requesting the documentation. RDSA will need the written documentation on the non-cash gift. We will provide substantiation for both the cash and non-cash donations in the form of the Thank You Letter/receipt.

### Materials & Resources

**Can RDSA provide any brochures or giveaways for my fundraiser?**

For Rare ACTIVist we are more than happy to send you some of our brochures. Email support to submit your request. Please include a link to your Rare ACTIVist Fundraising page.

**I'd like hats, t-shirts, and more products with the RDSA brand. Where can I go?**

In order to qualify for our branded merchandise, we encourage you to link your GivenGain fundraising project to our Rare ACTIVist Rewards programme: [www.givengain.com/cc/rareactivist/](http://www.givengain.com/cc/rareactivist/) This way we can track and reward you as you move up the tiers.

**I'm a business or corporation looking for a more long term relationship with RDSA through a cause marketing campaign. Where can I find out more information?**

If your company is interested in partnership opportunities with RDSA, please visit our [website](http://www.rarediseases.co.za) or email us at [support@rarediseases.co.za](mailto:support@rarediseases.co.za)

### Hosting an Event Questions

**Can I request a speaker for my event? Can I receive a RDSA sign or banner to use at my event?**

Due to the overwhelming requests for representatives and event speakers, as well as banners and marketing collateral, we aren't always able to send an RDSA representative to your event. Therefore we have implemented a tiered level event participation list which indicates what we can commit to. Please refer to page 9.

**My question is not answered here. How can I contact you?**

We are here to help make your fundraiser a success! Please contact us with any questions you may have regarding your fundraiser at [support@rarediseases.co.za](mailto:support@rarediseases.co.za)



At RDSA, we hear from people, almost on a daily basis, about how rare diseases have impacted their lives. From early referral services to the support community comforting our patients, we strive to provide help and hope for all patients affected by a rare diseases.

Everywhere we are seeing improvements in research and treatment, survivability, and support. [This is thanks to you!](#)

To our Rare ACTIVists, we convey our most sincere and heartfelt gratitude. Your generosity and dedication is what drives our mission and allows life-saving programs to help those truly in need. Thanks for directing your donations to RDSA.

Together we continue working for greater **empowerment through navigation, advocacy and engagement.**

# So, are you in?

Your support can make a difference in the lives of people battling rare diseases every day. **Visit our website** for more details.