

**SDS**  
UK

SHWACHMAN  
DIAMOND  
SYNDROME UK

# Shwachman Diamond Syndrome

## Fundraising Pack



be a   
Shwachman  
Diamond  
Syndrome  
Fundraiser



[www.sdsuk.org](http://www.sdsuk.org)



**Thank you for choosing to fundraise for SDSUK. SDS is so rare that every penny donated has a real impact on the individuals and families impacted by Shwachman Diamond Syndrome.**

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14. SDS info flyer front

## Included

- Ideas and advice to help you maximise your fundraising efforts
- QR Code for JustGiving
- Templates and Flyers
- Tips to raise awareness of SDS

## THOUGHTFUL QUOTE:

*'It's not the amount that matters but the meaning behind your donation'*

*-Jennifer Betts*





**SDSUK is run entirely by volunteer's and we exist to fulfil 4 specific missions:**

1

**Clinical Care:** To ensure that every child and family who receive an SDS diagnosis gets connected to the best possible clinical team and receives a treatment plan.

2

**Community:** To ensure that every SDS family receives emotional and practical support from the SDS community.

3

**Hard Times:** To ensure that every SDS family who needs to stay in a hospital gets support to be able to stay together if they need it.

4

**Research:** To support and fund research projects with the ultimate aim of having multiple SDS therapies available for SDS patients. Any proceeds from research endeavours get reinvested into more research.





**Let's get started!**  
**Set yourself a challenge!**  
**Be creative, be daring,**  
**or just be silly.**

Choose something you can safely do alone at home or in a local outdoor space. Ask friends to join your challenge or do it together as a family. Get creative - choose something that will be fun and challenging.

There are so many ways to fundraise. Whatever you do, big or small, you will make a difference.

So sell tickets, collect donations and let the fun commence!




**In 2022 Michelle took to the skies and Sky dived for SDSUK -but she's didn't stop there!**  
**In 2023 Michelle and a team of SDS runners completed the Loch Ness Marathon**

**claim Gift Aid  
&  
add an extra  
25p for every  
£1 you give.**







**Take on your own sponsored challenge. Whether you choose to do something you love or try something new, collect sponsorship and go all out to smash your target.**

- Complete twenty push ups every morning for a month or two
- Commit to walking, running or cycling a set distance to complete over a month or two
- Join in with the Super-Rare Together Walk on 25th February (visit [super-rare.org](http://super-rare.org) for more details)
- See if you can stay silent for a whole day
- Shave your head
- Wax your body or eyebrows
- Climb a peak or three!



**Challenge Yourself**

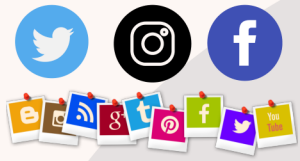
**Use a platform such as Zoom or Skype. Ask attendees to donate to your fundraising page.**

- Host a quiz
- Run a bingo night
- Like poetry? Hold a poetry slam!
- On your birthday - Why not ask people for donations instead of presents?
- Run an online gaming session



**Take it Online!**





**Bake sale**



**Community  
BBQ**



**Car boot  
sale**



Get crafty – turn  
your creativity  
into cash.



Get your school or  
company involved,  
have a pyjama day  
or a dress up day



**Sponsored  
sky dive**



**Marathon or  
park run**



**Trivia  
night**



**Host a raffle**



**Host a game  
night**

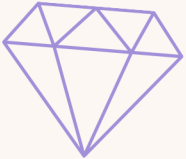
**Feel  
inspired?**





## What will your fundraising go towards this year?

- Holding an SDSUK Community Day for all families impacted by SDS
- Provide hotel stays for families when their children/relatives are in hospital away from home and need their family nearby
- Help with travel costs associated with appointments
- Funding for SDS Congress, bringing experts throughout the world together to help move research forward
- Community driven Research Partnership
- Research Partnerships with SDST



**Donate via  
Just Giving here**



[www.sdsuk.org](http://www.sdsuk.org)



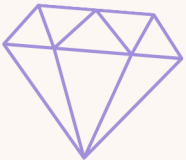
SHWACHMAN  
DIAMOND  
SYNDROME UK



## Now that you have some ideas for fundraising with SDS UK this year, let us help you take the next step.

We can help with the do's and don'ts of fundraising, logos, information on giftaid, physical assets and lots, lots more. By contacting us, we can email you through all the additional information you will need to be successful.

With any fundraiser, one of the most important parts is how you share and publicise. Make sure to use our hashtags so we can share everything you do.



Get in touch  
via our  
social media  
or email



[sds@sdsuk.org](mailto:sds@sdsuk.org)



[www.sdsuk.org](http://www.sdsuk.org)



## 2 Send individual messages

Be brave, and send individual messages to your family and friends, this could be face to face or direct messages via WhatsApp or email. Asking them to help kick off your fundraising. They'll be flattered that you asked them to support you, and it really will make a huge difference.

## 4 Start early

Fundraising early means more opportunity. More opportunity to fundraise or more opportunity to get people involved. Give yourself time to ask people, then remind them with social media posts and updates.

## 1 Make it personal

Speaking from the heart if you feel comfortable to share your story will resonate with people when asking for donations. Explain the impact of the money you raise, what the charity means to you, why do you want to support them? 'I'm fundraising for Shwachman Diamond Syndrome UK by [going on a walk/doing a skydive/your activity] I'm choosing to support SDSUK because...'

## 3 Talk about your target

Set yourself a target and talk about it. Remember if you fundraise £200 or more you get a Super Rare T-shirt. This is a great way to stay motivated. As you get half way, or approach the target - tell your friends about it and keep updating them. People will want to help you achieve your goal!

# Maximise your efforts





## 5 Get your workplace, school or university involved

This is a great way to raise awareness and fundraise. Have a pyjama day, have a bake sale. Some companies will match fund your fundraising or contribute to your personal fundraising. Drop an email to your boss or HR person and if they reply to say they can't contribute - that's the perfect time to ask if you can put a poster up or send an email around to your colleagues to ask for donations. You could even add a link to your fundraising page on to your email signature.

## 6 Share updates

Keep people up to date with your progress, this will keep them engaged. Send them photos, update your social media with videos and photos and tag the people in who has sponsored you. Do this in the weeks leading up to your challenge and on the day. Make the posts personal if you can. Share pictures, and the link to your donation page, this will remind people who haven't donated yet! Remember to tell people when you have completed your event. Tag the charity into the posts and use the #superrare2023

## 8 Shout about it

Put up the poster in this pack to promote your fundraising events on the ground.

## 7 Thank people when they donate

Publicly thank when someone donates on your page, post a Thank You image on their Facebook wall or tag them in your Instagram story. This reminds and encourages other people to donate too. After your challenge is complete, why not do a post/video thank you to everyone that has fundraised so far?

**SDSUK are  
with you !**





## **Before you get started fundraising, we want to make sure you are safe and supported doing it.**

Make sure that with all your fundraising efforts you follow all laws set out, and that all licenses and insurances are obtained.

Always follow health and safety regulations.


If you are handling money in public, there are guidelines that will be set out by your local council who can provide you with information on holding public events and gatherings.

The Fundraising regulator is always on hand to answer any questions you have, and as ever, you can always contact SDS UK, and we will always be happy to help.

## **The Legal Stuff**









Create a poster




Start early




What's your target




Make it personal




Share updates



Send individual messages



Involve school or work

- 
- Pick your favourite fundraising ideas
  - Set up a Just Giving page
  - Rally support and share what you're up to on social media with #SDSUK
  - Remember to tag in your charity
  - Get your 'I care for Super Rare' T-shirt

Your notes & ideas here.....

***Here are some helpful tips to help you start fundraising and reach your target***



**SDS**  
UK

SHWACHMAN  
DIAMOND  
SYNDROME UK

Be there for  
someone with SDS

# Shwachman Diamond Syndrome fundraiser



**EVENT NAME:**

**DATE AND TIME:**

**LOCATION:**



*be a*



Shwachman  
Diamond  
Syndrome  
Fundraiser



[www.sdsuk.org](http://www.sdsuk.org)



**SDS**  
UK


**SHWACHMAN  
DIAMOND  
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**Be there for  
someone with SDS**

# **Shwachman Diamond Syndrome is a rare genetic disease**



## **Common symptoms include**

- Pancreatic insufficiency
  - Reduced levels of fat soluble vitamins
  - Haematological abnormalities and reduced immune system
  - Increased risk of developing blood cancers such as myelodysplastic syndrome (MDS) and acute myeloid leukaemia (AML)
  - Developmental delay with potential psychological and social problems
  - Skeletal abnormalities
  - Faltering growth / poor stature
  - Dental problems
- 

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**Did you know?**

SDS is so rare that  
everypart of a donation  
has a direct impact on  
patients lives

Patients have to travel  
to different hospitals or  
clinics often miles away  
from home for their  
specialist care

There are only  
2 specialist  
adult clinics in  
the UK

Help is desperately  
needed for funding  
research and generating  
awareness of this little  
known disease

77% of parents living with  
someone with a rare bone  
marrow condition often or  
always feel anxious about  
their childs condition

48% see friends and  
family members less  
regularly as a result of  
the condition

Peolpe living with a  
rare bone marrow  
condition are over 4  
times more likely to  
be lonely than the  
general population



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Findings from Rare Voices: A National Report  
on the Experiences of those with Rare  
Conditions Affecting the Bone Marrow.