



SDS
UK


SHWACHMAN
DIAMOND
SYNDROME UK

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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be a
**Shwachman
Diamond
Syndrome**
Fundraiser



www.sdsuk.org

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DIAMOND
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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.**