The Noonan Syndrome
Support Group, Inc.

Welcome to the Noonan Syndrome Support Group.

Read the Internet edition of the *Noonan Connection*.

Read the brochure for the next TNSSG meeting which will be held in only:
217 days, 22 hours, and 48 minutes

Noonan Syndrome is a condition which affects both children and adults. It is often associated with congenital heart disease and short stature.

- It is believed that one in 1000 children worldwide are born with this condition.
- Each day a child is born with the condition.
- It's possible that 1:100 people carry the gene yet are virtually unaffected and undiagnosed.
- Once affected, their is a 50/50 chance of passing the gene on to one or more of their children.
- It can also occur sporadically, presumably due to a new mutation.

Often called a "hidden" condition, the children affected may have no obvious casual signs to the onlooker, but the problems may be many and complex with no clinical test available. This is a genetic condition that can affect the heart, growth, blood clotting, mental and physical development. Affected individuals may have behavior problems, learning difficulties and many other anomalies. Noonan Syndrome is one of the most common of those conditions associated with congenital heart abnormality.

Still its exact cause remains unknown.....

What is the Noonan Syndrome Support Group, Inc.?

The Group is intended for people whose lives are touched by Noonan Syndrome, and want to exchange experiences and hopes regarding our children (or us). Associated professionals are also welcome.

- We offer support, networking and information.
- We aim to create greater awareness amongst professionals and the public at large.
- We support research into the many aspects of this complex condition.

The Group operates a list service (discussion forum). If you would like to subscribe, send an e-mail to listserv@home.ease.lsoft.com with only the following command in the message body:

subscribe noonan-syndrome

For more information on Noonan Syndrome and/or the Noonan Syndrome Support Group (including how you can help), click on any of the following choices.

Join Us
Group News
Our Intros
Chat Room
TNSSG Meeting
List of Contacts
Info. and Resources
Gallery of Stars

Contact us
Sign Guestbook
View Guestbook
Complete Survey
State Rep. Connection

Wanda Robinson,
The Noonan Syndrome Support Group, Inc.,

P.O.Box 145
Upperco, MD 21155, USA
1-888-686-2224 within the USA
or 410-374-5245
(Telephone service is funded by a grant from *The Genetech Foundation for Growth and Development*)
info@noonansyndrome.org

Noonan Syndrome WebRing

[Previous] [Next] [Random] [Next 5] [List Sites]

This site is hosted by GeoCities

16

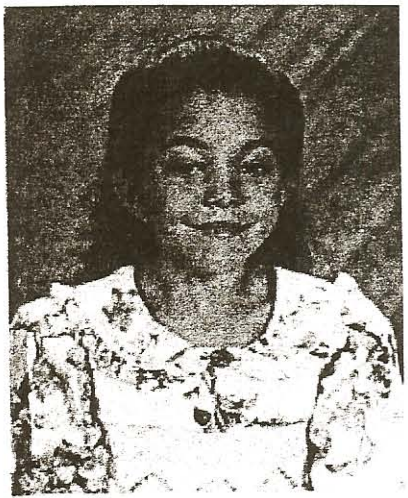
The Noonan Syndrome
Support Group, Inc.

Join (or Help) Us

What is the Noonan Syndrome Support Group, Inc.?

The Noonan Syndrome Support Group was founded in July, 1996. The Group is intended for people whose lives are touched by Noonan Syndrome, and want to exchange experiences and hopes regarding our children (or us). Associated professionals are also welcome.

- We offer support, networking and information.
- We aim to create greater awareness amongst professionals and the public at large.
- We support research into the many aspects of this complex condition.
- We operate a list service (discussion forum). If you would like to subscribe, and be a part of our family, send an e-mail to listserv@home.ease.lsoft.com with only the following command in the message body: subscribe noonan-syndrome
  (AOL subscribers also need to type a period "." in the subject line)
- Several of the subscribers prepared introductions of their families. These introductions are being updated periodically with new (or updated) information. Click here to view these introductions.
- We periodically publish a newsletter called "***The Noonan Connection***" is published periodically. To obtain a copy, contact us.
- We offer a toll free telephone number (1-888-686-2224) within the continental USA (the non-toll free number is 1-410-374-5245). This line has voice mail, so a message may be left when no one answers. This service is funded by a grant from *Genetech Foundation for Growth and Development.*
- For the latest group news, click here.

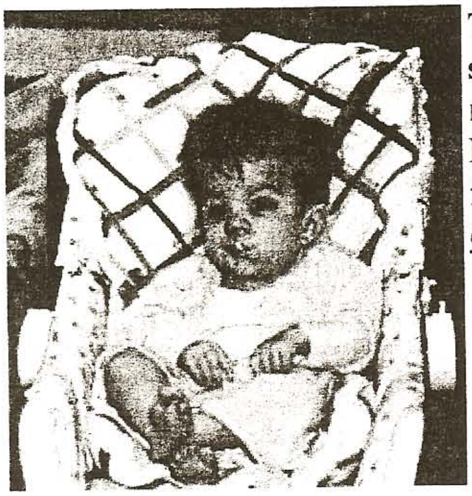


How can you be helped (or help us)?

This support group is still in its infancy, so we would like you to let us know how we can best help you!

We would like for all professionals working in the field of Noonan Syndrome to feel free to participate in this group. (We can use this space to announce any upcoming classes, clinics, seminars, camps, etc. that could benefit those with Noonan Syndrome.)

All financial contributions (or information regarding possible grants) are gratefully accepted, and needed. They will help the next family that needs information about Noonan Syndrome...



Those afflicted with Noonan Syndrome want the same as others ... to live life to the fullest and reach their true potential. Please remember Noonan Syndrome and help us to help these families - you can help! For further information, contact us.