THE NOONAN CONNECTION

The Noonan Syndrome Support Group, Inc. January 2003

HELLO FROM THE PRESIDENT

A lot has happened in the last year, so much in fact that it is hard to believe that it was only a year ago that Darcie had her 2nd ACM Decompression surgery. Now in 11th grade, with a learners permit and a cellular phone, Darcie is doing well. Recently Darcie was a bumblebee in a school production of Alice in Wonderland, she continues to sing in the school chorus and travel chorus and still dreams of getting one of the coveted spots in the ensemble in her senior year. Darcie is very involved in her church youth group, and also is the 'youth chaplain' for the FLYP (Fellowship of Lutheran Young People) board. Chris, Darcie's younger brother, thinks high school is much better than middle school! Dave and I think they are growing up way too fast!

If this last month is any indication, 2003 promises to be an exciting year, Chris Butler from Australia blew into town for 24 hours on his way across the United States. In the short amount of time he was here we were able to get together with several other families affected by Noonan syndrome. While Dave and Chris keep the home fires burning, Darcie and I will travel to Minnesota in February to participate in a fundraiser hosted by families involved in the Minnesota chapter of The Noonan Syndrome Support Group, Inc. I still have 3 more sessions of Partners in Policy Making, along with several important conferences that I would like to attend this year.

We are considering the benefits we could reap if TNSSG set up a blood and tissue bank. Having a TNSSG-controlled Central Repository could benefit all those directly affected by Noonan Syndrome by giving TNSSG the ability to help advance research in a more timely manner. It simplifies the research process--from sharing of biomedical material/data to IRB issues. I have talked to several of our medical advisors and they fully support this idea. Of course this would add to the focus of the group—adding research to our goals. The biggest consideration would ultimately be the amount of funds needed to make a TNSSG Central Repository a reality. I'll share more on this in the months to come.

Wanda H. Robinson

INSIDE

HURRY! THIS WILL BE YOUR LAST ISSUE, UNLESS YOU RETURN THE FORM ON PAGE 15! RENEW TODAY! DO NOT BE KEPT IN THE DARK AGAIN!

IMPORTANT INFORMATION INSIDE

Renew today! This could be your last issue (page 15).

Want to hear what the speakers said at the 2002 Noonan Syndrome conference?

You can now order a compact disc of each speaker. Each disc features one speaker. Each disc is approximately 60 minutes long. See ordering information sheet enclosed. **(page 13)**

Want people with Noonan syndrome to call you?

Simply fill in and return the enclosed contact data sheet . **(page 15)**

Want to talk to other people affected by Noonan syndrome?

Join our list serv (s). Look for additional information on page 9 and 12. **(page 12)**

THE NOONAN SYNDROME SUPPORT GROUP, Inc.
A Non-Profit Organization
We reach around the world!
Founder and President: Wanda Robinson
Vice President: Dave Robinson
Secretary: Pamela Hauck
Medical Advisor: Dr. J. Noonan

The Noonan Syndrome Support Group , Inc. was founded in June 1996, by Wanda Robinson.

We offer information and support to those whose lives are touched by Noonan syndrome. The group is self funded. Contributions are gratefully accepted and will help the next family to receive information about Noonan syndrome.

You can reach us at:
E-mail: **wandar@bellatlantic.net**
Or:
info@noonansyndrome.org
Web page:
http://www.noonansyndrome.org
Mail:
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Telecommunication service is Funded by the Minnesota Chapter of TNSSG, Inc.

1-888-686-2224 within the United States or

1-410-374-5245 outside of the United States

This newsletter is intended to provide basic information about Noonan syndrome. It is not intended to, nor does it, constitute medical or other advice. Readers are warned not to take any action with regard to medical treatment or otherwise based on the information in this brochure without first consulting a physician. The Noonan Syndrome Support Group, Inc. does not promote or recommend any treatment, therapy, institution or health care plan. The information contained in this brochure is intended to be for your general education and information only and not for use in pursuing treatment or course of action. Ultimately, the course of action in treating a given patient must be individualized after a thorough discussion with the patient's physician's.

You are more than welcome to plagiarize, as you see fit!

Did you know these characteristics are common in Noonan syndrome?

Clinical Characteristics
Short stature (2 SD below mean)
Typical facies
Triangular shape of face
Prominent brow
Hypertelorism
Epicanthus
Antimongoloid palpebral slant
Ptosis
Depressed nasal bridge
Broad apex nasi
Low-set and/or malformed ears
High-arched palate
Neck
Short
Webbing
Low hairline
Chest
Shield-like
Wide-spaced nipples
Pectus exacavatum
Cardiac abnormalities
Pulmonic stenosis (PS)
PS and ventricular septal defect
Atrial septal defect (ASD)
ASD with anomalous pulmonary venous return
Endocardial cushion defect (ECD)
ECD + patent ductus arteriosus and mitral insufficiency
Both PS and ASD
Patent ductus arteriosus (PDA)
Undiagnosed heart disease
Incompletely evaluated
Extremities
Cubitus valgus
Gracile fingers
Short stubby fingers
Lymphedema
Dystrophic nails
Shortened fourth metacarpal(s)
Clinodactyly of fifth finger(s)
Palmar simian crease
Undescended testes
Delayed puberty
Skeletal retardation
Cognitive development
Learning disability
Cognitive disability
Normal **Intrauterine growth retardation**
Renal collecting system
Normal karyotype

WE NEED YOUR HELP. IF YOU LIVE OUTSIDE THE USA?

Would you be willing to photo copy the Noonan Connection and mail it to other people in your country? It has become to expensive to mail each edition of The Noonan Connection out of country.

An edited edition of The Noonan Connection is available online. 28 people in the UK will receive this edition thanks to the efforts of **Michelle Ellis**, we would also like to thank (Simon Bland of) East Surrey College, Redhill, Surrey, U.K for kindly photocopying this newsletter.

Contact: wandar@bellatlantic.net if you can help

OUTSIDE THE USA: UPDATE FROM Michelle Ellis

After returning from such a great conference, I had renewed determination to help make a difference.

I rang Wanda and asked her if there was anything more that I could do from so far away in the UK. Wanda explained that one of the main costs to the group was sending newsletters, and other mailings overseas, and if I could help with sending the newsletters to the UK, then that would be great. I was amazed to hear that it cost around $6 just to send a newsletter to the UK from the US. I jumped at the chance!

I then set about arranging photocopying, envelopes, labels and postage stamps. I met my old college lecturer in town and he offered to copy the newsletter! I then found a wholesaler where I brought envelopes and labels. Postage stamps cost around $0.40 each. I first mailed the newsletter out in September, to 34 people and in October, I sent the order and contact form. It doesn't take much time or money, but is of course such a great help to the group, saving precious money that can be used more effectively elsewhere.

Note: As of January 2003 TNSSG, Inc. has not been contacted by anyone living outside the USA that is willing to help in this way.

TOGETHER

Debbie Smith, West Falls, NY

Thanks for responding. I really would like to see if there is enough interest in the Buffalo area to organize a walk in the spring/summer of 2003. Perhaps we could also have a pot luck picnic after the walk to get to know each other. As far as I know there are no small groups getting together in this area.

I would really appreciate you sending out post cards asking anyone interested to contact me. Debbie Smith 716/667/2602

e-mail: contpaper@pcom.net

Thanks again for your help with this. I will keep you informed of the progress.

Debbie

Stitches lead to quilt project

Nancy S. Naugle writes:

"I am proposing a quilt project to be completed previous to the next conference. I would like each individual (or parent) with NS to make a unique square to contribute to our Noonie Quilt. Individual squares will add to the "individuality" of the Noonie Quilt. On each square (somewhere)

I would like to include information of the person with NS (I.E. Name, place of residence, and age.).

If you would like to contribute a square to the project please contact me (Nancy Naugle) at (856) 235-0959.

If I'm not available please leave a message with your name, phone number, and you are calling because you wish to contribute a square to the Noonie quilt.

From the Noonan Syndrome Listserve I have had 21 responses. I think it is feasible. If you have already contacted me initially via e-mail that is sufficient. I will be getting back to everyone either via e-mail or phone to let them know the details (size of the square, and address to send it to). Even if you have no sewing ability, and wish to have your child/self represented on the quilt you can contact me. There are a few people who have offered to make an extra square in case there are those who really don't think they could accomplish sewing a square.

It is so neat to be a part of a caring cohesive group, and this is one of those things that is really neat to become / be a part of....SO.....

COME ON FOLKS.... WE CAN DO THIS!

Thanks in advance,

Nancy S. Naugle--->CM 1 successfully decompressed 4/2/01, mom to Brenda 11 years old NS + Budd-Chiari successfully decompressed 4/13/00, and Glenn 13 years old CM 1 (minimally herniated) successfully decompressed 8/22/01 - still watching two syrinxs in his spine....in NJ, USA."

If you live in the Denver area,

Kelly Mayr writes: ***Noonan Syndrome has a local face***

When your child is diagnosed with Noonan Syndrome -a little known and little understood condition -it can be frightening and disheartening.

I understand this first-hand; I am the mother of a two-year old daughter who has Noonan Syndrome. My name is Kelly Mayr, and we live in Highlands Ranch, just south of Denver.

I've gone through the medical fact-finding, the investigation of resources and support available, and the discovery of the many ways - major and minor -that parenting can change with a child with Noonan Syndrome. But I've also learned that adjusting-to this condition can be rewarding; often positive, and-much easier with knowledge and-support.

That's why I am-setting up a support group in the Denver area for parents who seek more information on this condition because their child or someone close to them - may be- or has been-diagnosed with Noonan syndrome. So if you want to talk first-hand to some-one local who- is already dealing with this issue, please phone me at (303} 471-2177 or e-mail me at KELLYM9999@AOL.COM.

To know that you are not the only one in this region coping with Noonan syndrome may be helpful. The more that we can share our knowledge, insights and experience, the more each of us will benefit. Please contact me.

Kelly Mayr

Stories of individuals with NS

Sue Walker writes:

Dear NS Adults,

Please forgive the formal greeting to those of you whom I have met – this message will also reach those whom I've not yet had the pleasure of meeting, at least not face-to-face.

As you may know, I am proposing to write a book that would be comprised primarily of stories of individuals with NS who have achieved adulthood, possibly also including the stories of some older teens as well. I propose this book in the hope that it would offer hope and comfort both to members of the TNSSG "family," as well as others in need of hope and support as they try to look into their children's futures.

The purpose of this message is to determine how many of you would be willing to share your story in print for the benefit of others – both other NS adults and parents, friends, and families of those who have not yet reached adulthood, and who are uncertain as to what future awaits their loved ones as they grow older.

The book is as yet untitled, as I am reluctant even to compose a "working title" until I know that the book is possible. It will only be possible with the permission and cooperation of a fairly large group of adults with NS who are willing to let their stories be made public. For anyone who does not wish their name to be made public, it is my intent to change the names of the participants in such a way that your privacy will be protected.

Please e-mail me ASAP at hswalker@techie.com to let me know if you are willing to participate, or even to discuss the possibility of participating. I truly believe that your stories, compiled in book format, would be of great value to others living with a diagnosis of NS, either their own or their friends and loved ones.

I hope to hear from you soon – thank you in advance for the thought and consideration that you will put into your decision (and hopefully into your participation).

Sincerely,

Sue Walker

Richmond, VA USA

Mom to Michael (23, NS), Shannon (27, possible mild NS), and Helen (37, no NS) and Nana to Kristen, 19 months, who sings in the car like her Nana

FROM THE HEART

MY SON WAS MISDIAGNOSED

By: Anette Napolitano

My son was misdiagnosed with "possible Noonan syndrome" almost exactly a year ago. His facial features were mildly distorted at 2 days after birth, he had 3 heart defects and 2 intestine defects that were unheard of together, he had a long and difficult birth and when he was born no one thought there was a problem until a day later when his heart murmur was so pronounced. He has had 2 heart surgeries and 3 intestine surgeries. I week after they speculated "noonans" the chief geneticist recanted what they had said and said that was there best guess at the time but genetic blood chromosome testing revealed a rare chromosome variance that non one has been reported with before. That same day they called us and our sons heart surgeon at ucsf to inform us of the mistake. Ironically that same day it was found out by the medical professionals ,and told to us that , they! had just found out that noonans is a gene variance on another chromosome, that my son does not have any problems with, and two of the cardiologists were surprised that we were ever even told there was a suspicion of this syndrome and that we should of never been told this. The genesis's were so sure his chromosomes were normal because I had a benign amniocentesis at 18 wks of pregnancy and that normally rules out 99% of all chromosome abnormalities this is why < we guess they jumped the gun on a speculation of noonans>.

They actually started recanting on there diagnosis after the intestine defects appeared <after their 5 minute visual evaluation of him at 2 days old.

The initial Drs that examined him gave him 8&9 apgar scores and did not think anything abnormal about him. It was only when he was transferred to a different kaiser that they thought his features were a little dysmorphic. He had er surgery on his intestines. I am writing you this because of the mistake they made with our son. My son is now one years old and looks like his parents and brother. He is a little delayed because of all the surgeries but our neurologist does not think he will be further affected by this chromosome variance [actually me and my husband can have the same variance but we have not been tested yet.} He told us that he does not look "dysmorphic "and therefore he thinks it is minor. My son is growing healthier and bigger everyday . I will always remember looking on your web site when they misdiagnosed him and being completely confused .

I looked your website up again because I am afraid that since there was no available test to reveal this syndrome that more children will be labeled with this syndrome wrongly and that a different genetic disorder [or not} could be the problem and may result in wrong treatments and expectations.

My experience was awful and genetics never apologized for their mistakes but did write a letter stating noonans syndrome was not his diagnosis and the rare chromosome problem explained his medical problems. I noticed that there are many more babies on your website and most of them look "normal".

I would hope you would relay my story to the parents of these children so that they may inquire when possible testing may be available.

Kids DO NOT NEED TO LABELED especially incorrectly. I have a copy of my sons medical chart and also found out that genetics were only speculating on this diagnosis. For one week we thought my son had this. This is unfair and I hope no one has to go through what we went through.

A lawsuit of negligence of this and many other errors is pending. I am now trying to get my experience across so that geneticist think twice about labeling a child before knowing the facts. I think a five minute examination was ridiculous and since there was no testing for this, what is the point for any of those children to be labeled?

Please, please pass this on so that everyone of those children get the correct diagnosis that they will have to live with for the rest of there lives.

"A disability label is simply the jargon used when making a medical diagnosis, and a sociopolitical passport that allows entry into the service system"

These are some of the more common characteristics found in Noonan syndrome and Cardiofaciocutaneous Syndrome

Atrial Septal Defect (ASD)
Cognitive Disability
Delayed Puberty
Depressed Nasal Bridge
High-Arched Palate
Hypertelorism
Hypertrophic Cardiomyopathy
Hypotonia
Learning Disability
Patent Ductus Arteriosus (PDA)
Pectus Exacavatum
PS And Ventricular Septal Defect
Ptosis
Pulmonic Stenosis
Seizures
Short Stature
Small Stenotic Ear Canals

IN THE NEWS….. NOONAN SYNDROME

GeneDx, Inc.

207 Perry Parkway
Gaithersburg, MD 20877
Phone 301-519-2100
Fax 301-519-2892
E-mail: genedx@genedx.com
Http://www.genedx.com

In some cases the DNA test directly detects an abnormality, called a mutation, in the gene, and the test is better than 99% accurate.

In other cases, the DNA test is unable to identify an abnormality although the abnormality may still exist. This event may be due to our current lack of knowledge of the complete gene structure or an inability of the current technology to identify certain types of changes (mutations) in the gene.

GeneDx, Inc. will look for changes in regions of the PTPN11 gene where 59% of patients with familial Noonan syndrome and 37% of individuals with sporadic Noonan syndrome have been shown to have mutations. Using our testing approach, 77% of published mutations would be detected by initially examining only two specific parts of the PTPN11 gene (exons 3 and 8). The remaining 23% of reported mutations would be identified by sequencing the remainder of the gene.

Considering that some cases of Noonan Syndrome are caused by mutation in another, yet-to-be identified gene, our testing in exons 3 and 8 of PTPN11 has chance of 35% of finding the mutation.

Testing the remainder of the gene will increase that chance to approximately 50%

(Please note The GeneDx, Inc. web site states the cost for this test is $500.00 for examining only two specific parts of the PTPN11 gene (exons 3 and 8). If additional testing is required additional costs would be involved.

Ultrasound Obstet Gynecol 2002; 19: 51-55

Poor prenatal detection rate of cardiac anomalies in Noonan syndrome

M. MENASHE, R. ARBEL, D. RAVEH, R. ACHIRONS and S. YAGEL

Departments of Obstetrics and Gynecology, ' Hadassah University Hospital Mt Scopus and Hadassah University Hospital, Ein Karem, Department of Internal Medicine, Sha'arei Tzedek Medical Center, Jerusalem and Department of Obstetrics and Gynecology, Chaim Sheba Medical Center, Tel-Hashomer, Israel

KEYWORDS : Congenital heart disease, Noonan syndrome, Prenatal diagnosis

ABSTRACT

Background The wide variation and nonspecific nature of many of the associated ultrasonographic findings complicate prenatal diagnosis of Noonan syndrome. The aim of the present study was to define the rate of prenatal diagnosis of heart malformations in cases diagnosed postnatally with Noonan syndrome.

Methods English-Language literature review of 29 cases of Noonan syndrome examined prenatally with confirmed postnatal diagnosis and four case reports from our center.

Results Cases were evaluated for cervical spine pathologies, cardiac anomalies and other pathological findings, including hydrops fetalis and polyhydramnios. Cardiac anomalies were suspected in only nine of 33 cases; three of these were associated with cystic hygroma. Cardiac anomalies were eventually diagnosed in 31/33 cases postnatally. Polyhydramnios was diagnosed in 19/33 cases in the third trimester, and hydrops fetalis was detected in eight of 33. Cystic hygroma was present in a total of nine cases at mid-trimester.

Conclusions Noonan syndrome is characterized by late- onset and progressive pathologies, particularly the associated cardiac anomalies, which develop through the course of gestation and postnatal life. This complicates or precludes pre- natal diagnosis at mid-trimester or at any time in the prenatal period, and partly explains the low rate of detection of fetal cardiac lesions in this syndrome.

Clinical manifestations of Noonan syndrome

Digilio MC, Marino B. Clinical manifestations of Noonan syndrome. Images Paediatr Cardiol 2001;7:19-30 19

IMAGES **in Paediatric Cardiology**
Invited article
Digilio MC, Marino B. Clinical manifestations of Noonan syndrome. Images Paediatr Cardiol 2001;7:19-30

Medical Genetics and Pediatric Cardiology, Bambino Gesù Hospital, Rome

MeSH

Noonan syndrome clinical genetics heart defects, congenital genetic counselling

Abstract

Noonan syndrome is a common genetic disorder characterized by facial anomalies, congenital heart defect, short stature, webbed neck, chest deformities and undescended testes. The phenotypic expression of Noonan syndrome is

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NEWS ABOUT NOONAN SYNDROME Continued

(Continued from page 5)

extremely variable, with some affected subjects showing only minor features of the syndrome. Cardiac malformations are also heterogeneous. Pulmonary stenosis, with or without dysplastic pulmonary valve and hypertrophic cardiomyopathy, are the "classic" cardiac defects reported in Noonan syndrome. However, atrial septal defect, atrioventricular septal defect, left-sided obstructive lesions, tetralogy of Fallot and patent ductus arteriosus have also been described. Autosomal dominant inheritance has been documented in some families, although many cases appear to be sporadic.

The diagnosis of Noonan syndrome is at present purely clinical, because a "diagnostic" test is not available. Indeed, although a gene for Noonan syndrome has
been recently mapped by linkage analysis to chromosome 12q, the gene or genes of
the syndrome have not been yet cloned.

"This is a well written article, with excellent pictures. "

This article is available online:

"Dear Maria,

I have no objection whatsoever for the paper to be included in their information package. I suggest that you send them/they can download the PDF version for easy printing (freely available on the journal website)

Victor"

OR, include a request for this article by using the TNSSG, Inc. order form.

Molecular And Cytogenetic Evidence That Cardiofaciocutaneous (Cfc) Syndrome Is Distinct From Noonan Syndrome (Ns) And That Its Locus Is Not In The Chromosome Region 12q21.2q22

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[2] Centro de Genética Médica, Universidade Federal de São Paulo-Escola Paulista de Medicina, São Paulo, Brazil;
[3] University of Utah, Salt Lake City, USA

Cardiofaciocutaneous (CFC) syndrome, described in 1986 by Reynolds et al., is a multiple congenital anomalies/mental retardation syndrome characterized by congenital heart defects, characteristic facial appearance, short stature, ectodermal abnormalities, and mental retardation. All reported cases are sporadic, have apparent normal chromosomes, and were born to non-consanguineous parents. CFC syndrome's main differential diagnosis is made with Noonan syndrome (NS). CFC and NS share several manifestations, most notably cardiac defects, similar craniofacial appearance and growth retardation. However, other clinical aspects such as degree of mental impairment, speech delay, ectodermal abnormalities, and severity of failure to thrive, can distinguish the two conditions.

Recently, two patients with a CFC-like phenotype and the same deletion on the long arm of chromosome 12 (12q21.2q22) have been reported [Rauen et al., 2000 and 2002]. The CFC syndrome diagnosis was proposed in both cases, although they were not typical patients. In order to verify the presence of microdeletions within this area in typical CFC patients, we performed fluorescent in situ hybridization (FISH) analysis with 12 BAC probes in 17 typical CFC patients. No microdeletions were found.

The finding of missence mutations of the PTPN11 gene in 45-50% of NS patients, with penetrance of almost 100% [Tartaglia et al., 2001 and 2002], strongly suggests that mutations of the PTPN11 are one of the causes of NS. We have sequenced the entire coding-region of the PTPN11, as well as its intron boundary regions, and studied its cDNA in 10 typical cases of the CFC syndrome. No base changes or deletions were detected.

Based on the above findings we conclude: a) that the region 12q21.2q22 is not a candidate region for the CFC syndrome and that the two patients presenting this deletion may represent another chromosomal syndrome with some resemblance to the CFC syndrome; b) that PTPN11 mutations or deletions are not found in CFC patients, supporting the contention that CFC and Noonan syndromes are distinct genetic entities.

Acknowledgments: we thank The CFC Family Network and it's president, Brenda Conger, for financial support and referral of patients, and doctors D Pallos, G Corona, G Scarano, J Sanchez, L Garavelli and M Piccione for referral of patients.

RENEW TODAY.

REMEMBER TO SEND IN YOUR RENEWAL (page 15).

THIS GUARANTEES THAT YOU WILL CONTINUE TO RECEIVE VALUABLE INFORMATION FROM THE NOONAN SYNDROME SUPPORT GROUP, Inc.

Thank you to the following people, companies and foundations for their continued support. They are making a difference.

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Peter & Susan Schaefer
In Memory of Betty Kapetanakis
Sherry Novik, Bob Roden and Natilie Roden
In Memory of Marguerite Koken
Evelyn Jones
Michael and Ellen Ryan
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Terry Gordon
Catherine Anne Trimboli
William and Helen Trimboli
In Memory of Cory Ellis
Ward and Samira Harrison

Mary Knight

THANK YOU TO THE FOLLOWING PEOPLE FOR THERE SUPPORT IN 2002.

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(Continued from page 7)

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Nikki Keef
Margaret Kennedy
Harriet Kessler
Renee Khatami
Perry King
Mary Lou Knight
Jim Knight
Bernd Koken
Timothy Krebes
Eric Kunz
William Kwochko
Pat Lage
Jill Lambert
Connie Larkin
Jody Layman
Adrienne Lehtinen
Paul Lenauer
Lilian Leung
Rebecca Linton
Barbara Lippe
Paula Lithander
Esther Litman
Yvette Livingston
Larry Lorenzi
Mike Lucarelli
Shirley Lyons
David Maag
Kathleen Madigan
Alexander Manganiello
Linda Manglass
Wahid Maqsudi
Edna Maravilla
George Markopoulos
Melissa Marlin
Louis Marrelli
Melinda Martin
Walter Mattson
Kelly Mayr
Gene Mcdavid
Ginnie Mcdrew
Jennifer Mcneal
Marian Meed
Mike Meents
Ronald Meleleu
Ronald Meleleu
Florencia Mendoza,
William Merchant
Lisa Merchants
Michele Metcalf
Thomas Michael
Joy Minns
Brenda Mitchel
Rick Moore
Richard Mucenic
Sandra Mullen
Barbara Murphy
Barbara Murphy
Lori Nalefski
Nancy Naugle
Brad Nees
Kathy Neira
Susan Nemeth
Chris Nettles
Brenda Newby
Joel Nixon
Mark Noel
Sandra Nolen
Jacqueline Noonan
Kess Noordam
Sherry Novick
Joseph Nowak
Oaks Preserve Staff
Mike O'brien
Patricia Lee O'brien
Barbara Olear
Kevin Oõmalley
Richard Ossias
Kim Paul
Rosemarie Pavilonis
Sarah Payne
Madeleine Pedersen
Dan Pedersen
Dana Pedersen
Alva Perry
Daralee Peterson
Arlene Peterson
Laila Petruzziello
Muriel Porcelli
Ray Powell
Joan Rainey
Jack Reade
Sandra Reed
Ronald Rice
Robin Richards-Szabo
Roderick Rivera
Louisa Robb
Brigid Roberts
Lottie Robinson
Wanda Robinson
Florence Rohlfing
Alicia Romano
Frances Romolo
Carol Roque
Lenora Rose
Jody Rosen
Arthur Rowe
Ronald Rutter
Mike Ryan
Deborah Sabin
Connie Sachar
Maria Santateresa-Fred
Susan Schaefer
Jean Schaeffer
Edna Schauer
John Schinker
Karen Schottenstein
Melvin Schrager
Ann Schreiner
Richard Schultz
Scott Schutt
Virginia Seaman
James Searle
Rene' Sewell
Phyllis Shaw
Leonard Sherwood
Sharon Siegel
Christina Silvera
Mary Allan Silvera
Maria Silvera
Kirt Simmons
Stephen Sluys
Debbie Smith
Deborah Smith
Eileen Smyth
Eugene Snell
Rabon Snell
Rabon Snell
Donna Snellgrove
Inna Snitkovskaya
Kimberly Sosebee
Sydney Spurgeon
Maggie Stayton
Heidi Stone
Elizabeth Suapengco
Sharon Suddeth
Marilyn Sumpter
Nancy Tafrow
John Thomas
Gary Thompson
Mary Timmins
Dana Timmons
Montiero Tinio
Herman Tobar
Evelyn Tonio
Elizabeth Tory
Gail Trabish
Shirley Trevains
William Trimboli
Patricia Trimboli
Tony Urmos
Hector Valdes Montero
Rich Vance
Widalis Vega Barreto
Lois Ely Vogel
Ted Von Glahn
Sue Walker
Jennifer Walker
Ted Walsh
Wilson Wearn
Ken Weiskopf
Mike Wessel
Jenni Wessels
Peg White
Mark Whitener
Sarah Whitt
Trina Wiener
Thomas Wiley
Karen Wizevich
Ursula Wollschlaeger
Marcia Wren
Chris Wright
Stella Xikis
Candice Young
Kirsten Young
Linda Zeh
Christine Zolt
Marlena Zumwalde

Alex Shapiro,
Betty Kapetanakis
Candece
Catherine Anne Trimboli
Christopher Merchant
Corey Ellis
Courtney Jarvis
Daniel Thompson
Danny Demag
Davis
Doris Reba
Dorothy Robinson
Grace
Heather Johnson
Helen Vastola
Isabella Rose Baldi
Jeffrey Minns
Jessica Silvera
Justin
Kenneth Koken
Marguerite Carol Doris Koken
Marlin L. Greiwe
Matthew Chapman
Mr. & Mrs. Joseph Nowak
Nicholas Edwards
Ryan Harlow
Scott Goldberg
Scott Wright
Tom Bondurant
William Chapman

These are the names of individuals that inspired giving in 2002.

Dr. Noonan Requests Your Help

Dear Noonan Syndrome Adult,

I am conducting some research on Noonan syndrome, with a particular emphasis on growth. This questionnaire will be helpful and the response kept confidential. Your identity will not be used in any possible publication.
If you are willing to participate, please complete this questionnaire and return it to me.

Thanks,
Dr. J. Noonan
Dept. of Ped Cardiology
Room MN 470
University of Kentucky Medical Center
800 Rose ST
Lexington, KY 40536-0298

Patient Questionnaire for Adult with Noonan syndrome.

Hi, This is a little questionnaire from the department of pediatric Cardiology of University of Kentucky Children's Hospital. It's a questionnaire about Noonan syndrome, it contains some questions about your health and well being. It will only take about 10 minutes. (If you feel uncomfortable with any question or don't know the answer, fell free to leave it open.) We would be very grateful if you would want to fill out this questionnaire on behalf of a research we are doing on Noonan syndrome (You could ask a family member to help you if you want} .
Thank you!

1. What is your sex?

2. What is your birth?

3. What is your height? (Measured without your shoes)

4. What is your weight?

5. What was your birth weight?

6. What was your birth height?

7. What was the duration of your mother's pregnancy (gestation)?

8. How far did you go in school? (what grade, high school, college, university?)

9. Did you ever have learning difficulties or special education?

10. Are you employed? (If not please explain reason)
What kind of job do you have?

11. Have you had any heart problem in the past? If yes did this problem require surgery?

12. How is your health at the present time?

13. When was the last time you saw a physician? (e. g.- primary health doctor, cardiologist, pediatrician)

14. Are you using any medication? (If yes please write down name and dose)

15. Have you ever used growth hormone? (If yes please tell us how long and at what age)

16. Are you married?

17. Do you have children? (If yes please write down sex and age of your children and if they have Noonan syndrome)

18. Does one of you family members have Noonan syndrome? Who?

19. For females: at what age did you start having your periods?
For males: At what age did your voice lower?

At what age did you start shaving?

20. Did you ever have any psychological problems?
(If yes please describe.)

At what age?

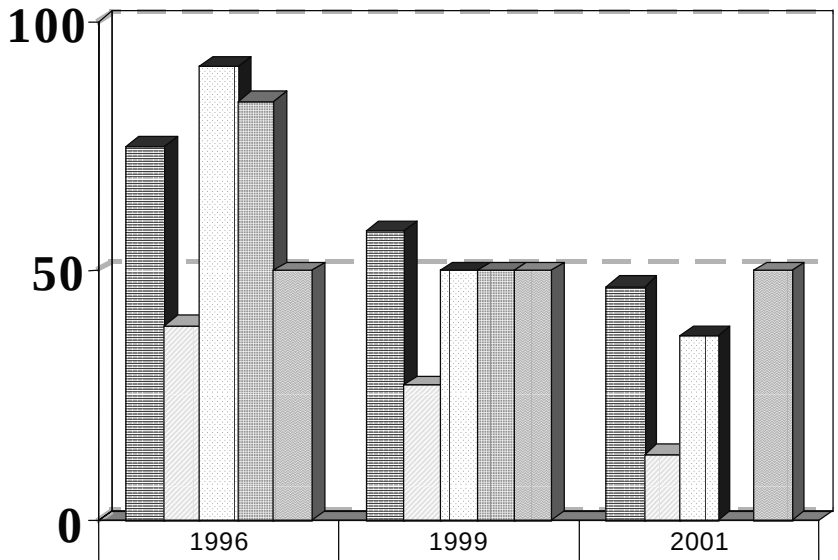
DID MARTHA GET WHAT SHE DESERVED?

**Martha is a 16-year-old girl who has Noonan syndrome.
When Martha was in 7th grade we started to learn more about what the laws meant with regard to her education. Martha has had an IEP since 2nd grade and, initially, it was simpler to believe everything the teachers/IEP team were saying. Martha has always preformed beyond what was expected. According to the IEP team Martha could be successful in collage and be able to fulfill her goal of becoming a nurse. The IEP team continued to report that Martha was making adequate progress and that the results obtained from academic testing* should not used to measure progress. The IEP team said that teacher observation and report card grades should measure progress.
Imagine the disappointment when it was learned that Martha had not been making adequate progress. In fact in some areas she was not even at age/ grade level.
In 10th grade Martha had the following results: Math Calculation 7th grade level. Reading Fluency Skills -7th grade level. Comprehension Skills - 9th grade level. Letter Word Identification Skills- 8th grade level. Written Expressions Skills - 10th grade level. Writing Fluency- 9th grade level. Spelling Skills - 6th grade level.
She continues to pass her classes, and has a 3.75 cumulative grade point average in the 11th grade.
Is it possible that the schools standards are not meeting the needs of people with learning disabilities? Is it possible that students with learning disabilities are graduating with a less than an adequate education?
Parents, just because you learn as much as you can to ensure your child's FAPE (Free Appropriate Public Education) does not mean it will happen.

* *Not her real name, but she is a real person, and this is actual data.

To be continued…...

***Woodcock Johnson Test of Achievement-Revised Percentile Ranks For Martha 1996-1999-2001**



	1996	1999	2001
Reading	75	58	47
Writing	39	27	13
Math	91	50	37
Knowledge	84	50	
Mean	50	50	50

♥ ****3nd REQUEST. WE NEED YOU****

♥ WE NEED YOUR HELP.

♥ PARENTS WRITE THE BOOK.

♥ MAKE A DIFFERENCE FOR OTHERS AFFECTED BY NOONAN SYNDROME

Dear Noonan Syndrome Support Group members,

The support group is creating an information packet about Noonan Syndrome that is designed for both the parents and individuals with Noonan Syndrome, as well as for their primary care physicians. Part of the information packet will contain personal narratives that describe particular aspects of Noonan Syndrome. If you would like to help us with this endeavor, please write a short personal story about one of the topics listed below. The stories should be single spaced, and no longer than 1 single-sided page. Please mail the narrative no later than October 20, 2002 on disk if possible, to the address at the bottom of this letter.

The topics include:

- *behavior
- growth
- *feeding difficulties
- vision
- teeth/dental
- other
- surgery
- cardiovascular/heart issues
- *facial appearance
- *skeletal anomalies
- skin
- coagulation/bleeding difficulties
- development
- cognitive ability

I have included a sample narrative from a separate support group as an example:

"When my son Joel's behavior became an obstacle in school and social situations, I consulted his neurologist and tried several medications to address mainly his aggressive behavior towards his peers and sibling. This aggressive behavior included pushing, pulling hair, and kicking. Several trials of different medications failed to help improve his behavior. After seeing the negative effects of some of these medications, and reading about the potential side effects, I decided to consult a natural nutritionist, who put Joel on a sugar free diet for his behavior, and dairy free diet to improve his asthma. I immediately saw changes in his behavior, which I attributed to this diet and the combination of vitamin supplements that the nutritionist recommended. His aggressive outbursts decreased, and his teachers and therapists commented on the changes in his behavior, and felt that he was much easier to work with since he started on the diet."

- CHARGE Parent Manual

* Thank you to the parents who wrote about these topics.

Thank you for your support.

Sincerely,
Scott Audlin
University of Maryland Genetic Counseling Student

Mail to:
Wanda Robinson
The Noonan Syndrome Support Group, Inc.
P.O. Box 145
Upperco, MD 21155, USA

Our Web site has been visited by over 100,000 people! We have given people another source for information! If not for the Web site, and all the attached material, people would still be looking for information about Noonan syndrome. A special thank you to Eugene K. As our former Web manager, he has created a place I am glad to call ours. Please help me welcome Jon W. as our new Web manager.

Adults with NS

This list is intended for adults (16 + years) with Noonan syndrome. A place to share information, and learn from each other. To Subscribe *****: ns-adults-Subscribe@yahoogroups.com
To Post message: ns-adults@yahoogroups.com
To Unsubscribe: ns-adults-unsubscribe@yahoogroups.com
List owner: ns-adults-owner@yahoogroups.com

Kids with NS (moderated by an adult with NS)

This is a place kids affected by Ns can talk. Only members can post, and because this is a group for kids.
Subscribe*****: nskids-subscribe@yahoogroups.com
Post message: nskids@yahoogroups.com
Unsubscribe: nskids-unsubscribe@yahoogroups.com
List owner::nskids-owner@yahoogroups.com

TNSSG information list

This site is a place to put things and information that might be of interest to people affected by Noonan syndrome.
This would include links to other web sites you think are important.
Subscribe *****: TNSSGINFO-subscribe@yahoogroups.com
Post message:TNSSGINFO@yahoogroups.com Unsubscribe: TNSSGINFO-unsubscribe@yahoogroups.com
List owner:TNSSGINFO-owner@yahoogroups.com

Chit chat list

This list is intended for people affected by Noonan syndrome who want a place to communicate or chit/chat. Birthdays or poems, or anything that is important to your family.
Subscribe*:tnssgchitchat-subscribe@yahoogroups.com
Post message: nssgchitchat@yahoogroups.com
Unsubscribe:tnssgchitchat-unsubscribe@yahoogroups.com
List owner:tnssgchitchat-owner@yahoogroups.com

The Noonan Connection (newsletter)

The Noonan Connection is the official news-letter for TNSSG, Inc.
Subscribe*****:noonanconnection-subscribe@yahoogroups.com
Post message:noonanconnection@yahoogroups.com Unsubscribe: noonanconnection-unsubscribe@yahoogroups.com List owner: noonanconnection-owner@yahoogroups.com

***You will then receive an e-mail requesting additional information. All requests must be approved to provide a more safe and private environment.**

WANT TO LEARN MORE ABOUT NOONAN SYNDROME?

♥READ A BOOK ABOUT NOONAN SYNDROME

♥LISTEN TO WHAT THE DOCTORS HAVE TO SAY ABOUT NOONAN SYNDROME

♥SEE WHAT'S COOKING...ONLY A FEW COOKBOOKS REMAIN ORDER TODAY

DESCRIPTION (FILL IN AND SEND WITH ORDER FORM)	#	$$ DUE
Growth Hormone in Noonan syndrome by Kees Noordam The studies presented in this thesis were funded by Pharmacia B.V., Woerden. Publication of this thesis was financially supported by Pharmacia B. V. , Woerden and FBW Kindergeneeskunde Nijmegen. - **$25.00 (Book)**		
Noonan Syndrome A Parents Guide- Excellent booklet written in easy to understand language, produced by The Noonan Syndrome Support Group, Inc.(1 Free with each parent package) - Additional books **$4.00 (Book)**		
Cómo Comprender El Síndrome De Noonan Guía Para Los Padres- Preparada Para El Grupo De Ayuda Del Síndrome De Noonan (Noonan Sydrome Support Group, Inc.) (1 Free with each parent package) - Additional books **$4.00 (Book)**		
The Many Faces of Noonan Syndrome Excellent booklet with photographs of people of various ages affected by Noonan syndrome. Produced by The Noonan Syndrome Support Group, Inc. -**$4.00 (Book)**		
Another Noonan Connection- A cookbook of favorite recipes (over 250 pages) from the families and friends of TNSSG, Inc. Produced by The Noonan Syndrome Support Group, Inc. **$10.00 (only**		
The Noonan Support Group Pin - This pin is shaped like a heart and within the heart is a box with the group's logo. The pin is set on a gold background. **$2.00**		
Noonan-syndrome Characteristics Development, and Intervention - by Dr. Stephen von Tetzchner, Center For Rare Disorders, The National Hospital, Norway: This book is a comprehensive guide that covers the many aspects of Noonan syndrome. **$20.00** "IF YOU ARE AFFECTED BY NOONAN SYNDROME YOU SHOULD OWN THIS BOOK" "THE MOST COMPREHENSIVE SOURCE OF INFORMATION ABOUT NOONAN SYNDROME		

(Compact Disks) Recording of individual speakers who presented at the 2002 Conference. Each disk is approximately 60 minutes long. $5.00 each	# @ $5.00	$$ DUE
CD: Dr. Steve Band: Director, Division of Pediatric Psychology and Neuropsychology, Mount Washington Pediatric Hospital One of the most common questions he has been asked by parents is how they can promote healthy self-esteem in their children with special needs. It is an important question that remains relevant today.		
CD: Dr. Thomas Baumgardner: Clinical neuropsychologist. He specializes in the assessment and treatment of children and adolescents with behavioral, learning, emotional, and cognitive disabilities. He is part of a multidisciplinary group of psychologists, psychiatrists, social workers, and behavioral pediatricians located at Johns Hopkins at Greenspring Station.		
CD: Dr. Bruce Gelb: The Arthur J. and Nelly Z. Cohen Professor of Pediatrics Professor of Human Genetics. Director Cardiovascular Genetics Program, Mt. Sinai School of Medicine, New York, NY.		
CD: Dr. Bryan Hall: Professor Emeritus Department of Pediatrics Division of Genetics and Dysmorphology, University of Kentucky, Lexington, KY. Special diagnostic interests: multiple congenital anomaly syndrome identification and teaching thereof.		
CD: Dr. Dolores Njoku: Pediatric Anesthesiologists on Staff at Johns Hopkins, Baltimore, MD. Research interests include the Immune effects of anesthetics		
CD: Dr. Jacqueline Noonan: University of Kentucky Medical Center, Lexington, KY. Professor of Pediatrics in the Division of Pediatric Cardiology.		
CD: **Dr. Alicia Romano:** Director of Pediatrics Endocrinology Our Lady of Mercy Medical Center Bronx, NY.		
CD: Dr. Frank E. Schafer :Associate Professor of Pediatrics, MCP Hahnemann University School of Medicine; Director General Hematology Clinic and Bleeding Disorders Program, St. Christopher's Hospital for Children Philadelphia, PA.		
CD: Dr Judith Allanson: Clinical geneticist with a longstanding interest in Noonan Syndrome. Her research focuses on the face: how it changes with age; how we evaluate facial appearance; how important knowledge of facial change is in the diagnosis of Noonan Syndrome.		

TNSSG ORDER FORM: PLEASE PRINT

DATE_____

NAME:

_____

MAILING ADDRESS: _____

CITY: _____, STATE: _____ ZIP: _____

AREA CODE : _____TELEPHONE NUMBER :_____

____ Check Enclosed (MAKE PAYABLE TO: TNSSG, Inc.)

OR

For your convenience we now accept credit cards:
Check card type: Discover ___ Visa ___ Master Card _____

_____

PRINT NAME AS IT APPEARS ON CREDIT CARD

4 DIGIT EXPIRATION DATE : _____ / ____ **MONTH / YEAR**

__ __ __ __ - __ __ __ __ - __ __ __ __ - __ __ __ __

ACCOUNT NUMBER

_____

AUTHORIZED CARDHOLDER SIGNATURE

IN US DOLLARS PLEASE INDICATE :

TOTAL FOR ITEMS PURCHASED $ _____
TOTAL SHIPPING COST # ITEMS X $ 3.00 = $ _____
TAX DEDUCTIBLE CONTRIBUTION + $ _____
TOTAL AMOUNT = $_____

Mail completed order form to:
TNSSG, Inc.
P O Box 145
Upperco, MD 21155

QUESTIONS?
Telephone:
888-686-2224
410-374-5245
Email:
wandar@bellatlantic.net
ORDER ON LINE:
HTTP://WWW.NOONANSYNDROME.ORG

2002-2003 TNSSG, Inc. MEMBER/CONTACT RENEWAL FORM

After you contact us for information, we add you on our mailing list to receive the Noonan Connection and other mailings. We have no recurring dues or fees for membership. Therefore, depend on your generous contributions to support our efforts to educate people about Noonan syndrome. . The only way of knowing if you are still interested in receiving this information is to periodically ask you to confirm your desire to receive information from The Noonan Syndrome Support Group, Inc. Our first Newsletter mailed in the fall of 1996 went to fewer than 50 people.

The Summer 2002 Noonan Connection was mailed to more than 1,600 people in 25 countries, again, made possible because of your generous contributions. We need to establish a way of assuring that we don't mail newsletters to people who are no longer interested in receiving information about Noonan syndrome and our group. Therefore, if you wish to remain on our mailing list, **you must** fill out and return this **MEMBER/ CONTACT RENEWAL FORM** . Additionally, the only way you can be added to or remain on our **People You Can Call List** (see attached) is to fill out a **MEMBER/CONTACT RENEWAL FORM** .

The people listed on the People You Can Call List have given TNSSG, Inc. permission to publish their contact information. Please be courteous when calling and remember to check time zones. The only way we can publish this information is with written permission.

***If you don't return this* 2002-2003 TNSSG, Inc. MEMBER/CONTACT RENEWAL FORM*, you will be removed from our files and our* People You Can Call List.**

PLEASE PRINT Only those people who did not return there renewal form in the last 3 months, need to fill out this form.

2002- 2003-MEMBER/CONTACT RENEWAL FORM

____ I want to continue to receive information from The Noonan Syndrome Support Group, Inc.
____ I want TNSSG, Inc. to send an information package to the following person.
____ I want to continue to be included on the People You Can Call List*.
____ I want to be added to the People You Can Call List*.

♥LAST NAME: _____ FIRST NAME: _____
♥MAILING ADDRESS:_____ _____
♥CITY: _____ STATE:_____ZIP:_____ COUNTRY: _____
♥PHONE NUMBER:_____ - _____ E-MAIL ADDRESS:_____
♥ UPDATE/CHANGE: _____

HOW ARE YOU AFFECTED? (please indicate)

♥____ Directly Affected (an adult with NS):____ Indirectly Affected (a parent or guardian of a child with NS.)
♥____ G.R.A.N.S(Grandparents Relatives Advocating for NS.): ___N.A.P.(Noonan Angel Parents/ People). (These people have had someone they love die from complications associated with NS.):____:Professionals (doctors, teachers etc. taking an interest in those affected by NS)

CHOOSE ONE IF YOU ARE PART OF THE PEOPLE YOU CAN CALL LIST

♥*ADD MY NAME TO THE CONTACT LIST AND WEB SITE CONTACT PAGE : _____
♥*ADD MY NAME TO THE CONTACT LIST ONLY (published in The Noonan Connection): ____
♥NAME OF PERSON AFFECTED WITH NS:_____DATE OF BIRTH: ___/___/___
___ Inherited: _____Sporadic Occurrence/ Mutation
♥NAME OF PERSON AFFECTED WITH NS:_____DATE OF BIRTH: ___/___/___
♥___ Inherited: _____Sporadic Occurrence/ Mutation
♥NAME OF PERSON AFFECTED WITH NS:_____DATE OF BIRTH: ___/___/___
♥___ Inherited: _____Sporadic Occurrence/ Mutation

I HEREBY AUTHORIZE RELEASE OF MY NAME, MY CHILD'S NAME AND THE INFORMATION ON THIS FORM TO THE NOONAN SYNDROME SUPPORT GROUP AND THE FAMILIES INVOLVED THEREIN.
♥SIGNATURE: _____ DATE: _____

Return completed form to:
TNSSG, Inc.
P O Box 145,
Upperco, MD 21155

QUESTIONS?
Telephone: 888-686-2224 OR 410-374-5245
Email: wandar@bellatlantic.net
HTTP://WWW.NOONANSYNDROME.ORG

THE NOONAN SYNDROME SUPPORT GROUP.
PO BOX 145
UPPERCO, MD 2115

NON-PROFIT
U.S. POSTAGE PAID
UPPERCO, MD
PERMIT # 13

INFORMATION YOU CAN USE FROM TNSSG. Inc.
NEW CD'S AVAILABLE
RENEW TODAY

The Noonan Syndrome Support Group, Needs Your Continued Support.

HERE ARE SOME OF THE WAYS YOU CAN SUPPORT TNSSG, INC.

- **MAKE A TAX DEDUCTIBLE CONTRIBUTION**
- **DESIGNATE TNSSG, INC. ON YOUR PLEDGE FORM WHEN GIVING TO THE UNITED WAY OR COMBINED FEDERAL CAMPAIGN**
- **ARRANGE FOR A MATCHING FUNDS DONATION THROUGH YOUR EMPLOYER**
- **HONOR A LOVED ONE OR CLOSE FRIEND WITH A BEQUEST IN THEIR NAME**
- **ORGANIZE AND PLAN A FUND RAISER**
- **PARTICIPATE IN A FUND RAISER**
- **MAIL INFORMATION TO OTHERS ABOUT NOONAN SYNDROME**
- **TALK TO OTHERS ABOUT NOONAN SYNDROME**
- **BECOME A CONTACT, FILL OUT THE ATTACHED CONTACT RELEASE INFORMATION FORM.**

DO SOMETHING -WE NEED YOUR CONTINUED SUPPORT- BE A PART OF THE SOLUTION

"The only disability is a bad attitude."