



Loose Connections

The Official Communications Link of the Ehlers-Danlos National Foundation

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Ehlers-Danlos National Foundation (EDNF) and National Organization for Rare Disorders (NORD) Announce Research Seed-Money Grants for Ehlers-Danlos Syndrome.

By Andrew McCluskey
Executive Director

National Organization for Rare Disorders (NORD) is accepting applications for one-year grants for clinical research studies related to the early detection, diagnosis or treatment of patients with Ehlers-Danlos Syndrome (EDS). The decision to work with NORD was approved by the board in January of this year. We anticipate funding successful applicants by October 2004, with two grants not to exceed \$30,000 for one year.

From Funds to Funding

The process involved in moving from having funds available for research to actually funding a project is complex. NORD is a non-profit voluntary health agency dedicated to the identification, treatment and cure of rare "orphan" diseases. They have a successful Research Grant Program that awards small "seed money" grants to academic researchers studying new treatments or diagnostic tests for rare diseases. The hope is that the results of these studies will be used to obtain funding from NIH (National Institutes of Health), FDA (Food & Drug Administration) or other funding agencies, or even to attract a corporate sponsor.

Finding the Best Researchers

In the center of this issue of Loose Connections you will find a copy of the request for proposals (RFP). This RFP has been advertised in leading medical journals and mailed to every university-affiliated hospital and medical school in the United States. A search for researchers who have published journal articles about EDS in the last 2 – 5 years has also been conducted in order to reach the most expert scientists. Research institutions in

Canada and Europe have also been notified of the RFP.

What do we mean when we talk about research? Princeton University defines it as "a search for knowledge." What kind of knowledge? The answer will be different depending upon whom you ask.

Gene Therapy

For many families with EDS, the ultimate hope when contemplating research is to find a cure, but again, what does this mean? They are likely imagining the eradication of the symptoms and the consequences of the disorder, something like finding a vaccine for smallpox. To better understand this concept we spoke with Melanie Pepin, MS, CGC at the Collagen Diagnostic Laboratory at the University of Washington.

EDS, like other genetic disorders, is caused by an error in a gene, an error in the DNA sequence. When this error is present, the protein made by the gene will be faulty. In EDS, the faulty protein is collagen. A complete cure will require the repair of the DNA error, or at least a way of circumventing the error. This approach falls under the loose heading of "Gene Therapy", and it is this type of research that is being aggressively pursued by the scientific community worldwide.

When gene therapy becomes available, it is likely that the technique or process will be applicable to many different genetic disorders. However, each individual disorder will need to be understood in its exact genetic mutation in order to benefit.

We Can Make a Difference

The study of gene therapy is a particularly costly process, involving highly trained individuals utilizing specialized equipment. This type of research is typically funded through multi million dollar grants from Government, private foundations or corporations. Although every dollar helps, it is unlikely that the EDS research dollar will have a significant impact on the success of this program.

However, the search for the exact genetic mutations that cause EDS is something we can impact significantly. Although this too is a costly process, through the establishment of seed grants, we can assist investigators in finding data that will enable them to secure even greater funding from the institutions mentioned above.

Finally, there is the need to improve treatment strategies and testing options for the 1.4 million people globally who suffer from EDS. The funding of clinicians to establish small clinical trials is essential in identifying and distributing knowledge. This is the kind of knowledge that will have an immediate impact on the daily lives of those who live with this disorder.

What Can You Do?

The two seed grants that are currently available as a result of EDNF funding are open to any academic researcher with an interest in EDS. These funds may be used to assist existing projects that are researching the genetic
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Editor

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President's Message

Happy New Year

By Robin Coppi, R.N., B.S.N.

During the holiday season, I took the opportunity to get in touch with friends and family, renew acquaintances, and reflect on the past year.

As some of us do, I made my New Years resolutions and sealed them with a toast. I anxiously began this year with the intentions of keeping my resolutions, and having the satisfaction that the previous year was complete with great memories and accomplishments.

As I pondered the future year, I realized that it is the same for the EDNF, which has a life of its own. Reflecting on the past year, full of change and progress we have had many accomplishments. Stopping to look back 10 years ago and where EDNF is positioned today, it is amazing so many great things have been done by so many giving individuals.

EDNF has produced quality products such as the Educational CD-ROM on Vascular EDS, Interactive Web site, Parent Teacher Guide, along with improved communication with members through surveys, and local group support. In response to local groups, the structure of groups changed and the focus on fundraising has been replaced to one of information. A Handbook for Local Group Leaders is now available.

The Board of Directors (BOD) "reflected" on the status of EDNF, as the year drew to a close. The Directors then made the "New Years Resolutions" to continue to pursue many new opportunities. Responding to member suggestions, there are new changes to the website. EDNF has a new professional appearance with

trade mark and logo, and the number one priority for this year is the beginning of research projects. Soon there will be improvements made to Loose Connections, to better reflect our member needs.

Other "resolutions" that will be occurring this year include representation of EDNF by Lynn Sanders in Washington D.C. as a member of the Coalition to the NIH, and representation by Maggie Buckley in Sacramento for the Pain Awareness month campaign. Both will increase the visibility of EDNF with legislatures and lawmakers.

As EDNF utilizes the volunteer services of various members, the flow of ideas and offers of help is extraordinary, not often seen in large organizations.

2004 will be another successful year because of the generous donations from many and the gifts of time and talent from several. In particular, the dedication of Linda Neumann Potash, the enthusiasm of Andrew McCluskey, and the hours of work from board members such as Charlotte Mecum with local groups, Peggy Snuggs author of the Parent Teacher Guide, and Judy Giddy-King who is planning our next conference. Overall the loyal support to EDNF, and the Mission Statement, along with open discussions, and teamwork from every individual on the Board of Directors has played a significant role in the shaping of EDNF.

The Board of Directors wishes each of you a personally great year, as we all can look forward to an exciting New Year for EDNF.

Research Seed-Money Grants for Ehlers-Danlos Syndrome...continued from page 1

makeup of EDS, but they are also available to physicians who are developing new treatments or devices. To quote from the RFP:

"Protocols that will focus on early detection, diagnosis, or treatment (pharmacological, devices, surgery, or dietary) will be given priority."

What this means is that if your physician is developing something that WORKS, then they may wish to apply for this money in order to further develop the approach. We ask every member reading this article to take the RFP from the center and to share it with your physician. The more we inform the medical community that the EDNF is in the business of funding research, the greater the likelihood that new treatments and solutions will be pursued.

These two grants are the start of what will become an ever-increasing program of research funding by the EDNF. The current growth in membership and subsequent increase in funding will allow us to devote more monies to research. Our relationship with NORD allows us to fund as many seed grants as the board deems appropriate, without increasing our staff overhead and administrative costs. If this approach is successful and we have the funding available, we could double the amount of research that we fund in 2005.

As the foundation grows, it is not unreasonable to project a future where we are in a position to fund a million dollar project ourselves. It is likely that the board of the EDNF will be made up of different faces when that happens, but we look forward to that day.

Executive Summary

By Andrew McCluskey, Executive Director

My goal in providing an executive summary is to give the readership of Loose Connections a feel for what the priorities of the national office have been and what they will be in the immediate future. As well as being a much-loved publication, Loose Connections remains a vital tool in maintaining contact with our members who do not use the Internet. It is also an excellent way of communicating with the health care community; it is easier to hand over a newsletter than a computer!

All Change

The last 6 months have seen a huge amount of change within the Foundation: new leadership, new look, new products, new strategies, and this is just the beginning. The steady growth in membership combined with the explosion in our Internet services, has dramatically increased the amount of information requests that we handle. So how have we managed to accommodate these changes without increasing the number of staff in the national office?

Progress

The 60% of the membership that have signed up for their free access to the members area at www.ednf.org are well aware of how we are doing it. The creation of our on-line community: the message board system, the contact database, e-mail and chat, have enabled the EDNF to unlock the potential that already existed within its membership. Members are now helping each other in ways that were impossible before the arrival of the Internet.

I cannot stress enough the importance of those members who are donating their time; whether that is contributing to the over 15,000 posts of information on the message boards or taking part in Local Groups. By participating you are directly contributing to the success of this organization.

Results

The launch of Peggy Snuggs' excellent Parent and Educator's Guide was a great way to start the year. The implementation of group software, (which allows group leaders to run

their own web pages and manage their own groups through the EDNF web site), is another example of how we are empowering individuals and devolving responsibility for our success to the membership itself.

The re-organization and subsequent growth in our local groups is a huge endorsement of the leadership and voluntary effort demonstrated by Charlotte Mecum, Director of Local Groups. With volunteer groups organizing the learning conference in July, pulling together research surveys, project managing the next CD-ROM and researching the sale of branded EDNF merchandise, we truly are becoming a member driven organization.

The funding of two \$30,000 grants this year for clinical research studies related to the early detection, diagnosis or treatment of patients with Ehlers-Danlos Syndrome, is perhaps the most exciting decision of all.

Thank You

Finally, I want to extend a personal thank you to everybody who has offered support to this office over the last 6 months. It has been one of the most challenging yet rewarding experiences of my life and I am looking forward to seeing what we can achieve by the end of 2004.

Ehlers-Danlos National Foundation Membership Services February 2004

On-line Information Networking

The secure members area at www.ednf.org has two distinct benefits to members of the EDNF.

1. Access to over 15,500 posts generated by the 1350 families who have been sharing their knowledge about EDS on the message board system. This information bank on EDS grows at a rate of over 50 new posts a day and it is searchable from the member's home page.
2. Access to the on-line networking database. Members can choose to share their information with other members of the foundation, get in touch with members local to them or those who have the same type of EDS.

Internet Services

Apart from access to the growing on-line community and information resource, members also receive the following:

- A free e-mail address @ednf.org
- On-line Calendar
- On-line Scheduler
- On-line Address Book
- On-line Chat
- On-line Contact Database
- Back issues of Loose Connections from 1996 to present

Local Groups

The EDNF currently has over 36 local groups

organizing throughout the United States. Each group has its own agenda and stated purpose. To find out more please visit our web site at www.ednf.org or look for group details published in Loose Connections.

Local Groups are fundamental to the success of the foundation and are actively supported by the national office. If there is no Local Group in your area we encourage you to consider starting one. We have a dedicated Director of Local Groups and excellent technology that makes starting and running a Local Group easier than it has ever been. To find out more, please send an email to Charlotte Mecum at charlotte@ednf.org

Educational Material

Over the last two years the Foundation has spent over \$150,000 on disseminating accurate information about EDS, hosted an international learning conference and attended seven different medical association conferences. The Foundation produces the following products which are distributed free to members of the EDNF:

- Leaflets covering the Types, Facts and Hereditary aspects of EDS
- Emergency Room CD-ROM – Focusing on the Vascular type of EDS
- Educator's & Parent's Guide

Coming in June 2004:

- CD-ROM covering all types of EDS

Loose Connections

Loose Connections, EDNF's newsletter, is published on a quarterly basis. We continually seek input from our members as well as health care professionals. At the present time we have a 3,000 print run, with a readership in excess of 10,000.

Conferences

EDNF has sponsored twelve national conferences since 1988. Eight of the conferences had either a research or educational focus with four conferences being a combination of both. Health care professionals, and those affected by EDS and their families are encouraged to attend. Our 14th national learning conference will be held July 15- 18, 2004 at the Hyatt Regency in Buffalo, NY.

Membership

EDNF membership is open to anyone who wishes to join. **A complimentary membership is available to ANYONE affected by EDS who wishes to become a member but cannot afford the membership dues.** If you are unable to afford the dues, please fill out the membership form and check the box marked Complimentary.

Physician Referral

EDNF does **not** yet have a physician referral program.

For people with EDS, life can be full of challenges. Some days just getting out of bed is challenge enough. Several months ago, I received a phone call with a challenge that while a little frightening, was extremely interesting to me and very exciting.

Before hiring Andrew to fill the position of Executive Director of the EDNF, the Board of Directors asked him to prepare a proposal of his vision for the Foundation. Foremost in this vision were the local groups and the part they will play in the EDNF's ability to carry out its mission. In his phone call to me, and in the many that would follow over the past months, he painted a picture of local groups across the country. Establishing their own mission statements to reflect the concerns and needs of the members and their communities, bringing awareness of EDS to individuals and health professionals, schools, government, local media and other organizations; providing accurate information and emotional support to individuals with EDS and their families, and all of this, in turn, leading to increased local group memberships, increased EDNF memberships, increased donations, sponsorships, and grants, resulting in the ability to fund more and more research until one day the final goal is reached, the cure for EDS.

This all sounded wonderful to me. Since I first received a diagnosis of EDS and then realized that I was not the only one who had it, I had wished for a time when people would no longer have to go through the frustration, confusion, depression and isolation I had lived with. I was not even aware the EDNF existed until 1994. Once I became involved by starting a local group, then becoming a board member and now holding the position of Director of Local Groups, the drive I have felt to help make a difference in the lives of individuals with EDS has become stronger and stronger. I do not want people to have to deal with this disorder alone. I want them to be able to receive an early and accurate diagnosis of EDS, receive proper treatment and not have to endure being told by family members, teachers, and especially doctors that their symptoms are all in their heads. I do not want lives to be lost to EDS because of the lack of knowledge about the disorder and how to manage it. So, of course, what Andrew was saying to me about the things that could be accomplished by effective, active local groups was inspiring and exciting - - but how could we make this happen?

That was the challenge. Andrew and I have spent many hours on the phone, planning the strategy and discussing results, and many hours working individually and as a team writing letters, articles for Loose Connections, rewriting the Group Leaders Handbook, writing

marketing plans, creating application forms for group organization and charter. We sent out over 50 packs of information detailing the new plan and structure for local groups. We have spent hours on the telephone with leaders of already organized groups and with individuals wanting to organize new groups, both of us speaking with each one several times. We have set up chat sessions for group leaders and group organizers - I spend one hour a week in a chat room (Andrew comes in when he can) so that they can discuss concerns, ideas, ask questions, helping and learning from each other. So far, the attendance of these sessions has been low, but we are hoping that as awareness of the sessions increases and they become more effective that the number of leaders joining in will increase. I am excited about the possibilities available to us through our web site. The groups and group leaders will soon be able to do amazing things in leading and managing their groups.

I have committed to spend at least 20 hours each week working on local group matters. I do not regret a single minute I devote to trying to make the vision and plan for the EDNF succeed. When I have felt disappointment at the slow rate at which things are happening, just talking with Andrew again about what can be, what local groups can do and where the EDNF is moving, renews my enthusiasm and excitement, and my amazement at how much has really been accomplished in a very short period of time. There are presently over 30 groups being organized or reorganized. Of these only 11 were already active or being organized at the time this new structure and plan began. I think that's pretty amazing! I have always been impatient. I am so eager for more and more groups all over the country to organize, to begin their missions, and for us to accomplish the great things that I now know are possible. I guess this challenge to give the needed time, effort, leadership and

continued on next page

Groups and Potential Organizers Who Received New Group Information Packs Since October 2003

Detroit	Philadelphia Branch	DC Area
Baltimore Branch	Pittsburgh, PA	Dover
Boston, MA	Abilene, TX	Florida Panhandle
St. Louis, MO	Dallas/Ft. Worth	Naples, FL
Omaha, NE	Houston	SE Florida
Central NJ Branch	Johnson City, TN	St. Petersburg
Southern New Jersey Branch	Provo, UT	Tampa Bay
Long Island, NY	Washington State	Atlanta Support Group
New York Metropolitan Branch	Eau Claire, WI	Cartersville, GA
Westchester County, NY	Madison Branch	Chicago Branch
Western New York Branch	Milwaukee Branch	Iowa Branch
WNY Outreach Group	Northern Alabama	Michiana Branch
Upper NY State	Southern Alabama	Central/Eastern Kentucky
Piedmont Triad Branch	Southern Arizona	Monroe, LA
Asheville & WNC Region	Greater Los Angeles	Washington DC Area
Wilmington, NC	Greater San Diego	Maryland
Northeast Ohio Branch	Northern California	Maine Support Group
Cincinnati, Ohio	Santa Barbara	Eliot, Maine
Center City Support Group	San Fernando Valley	Southeast Michigan
	Denver Support Group	

Active and Newly Organized Groups

*Indicates groups with message boards and web pages on new group software

*Alabama State Group - Julie Domian	*Western New York - Judy Giddy-King
*North Alabama EDS Group - Kelly Tinnon	Upper New York - JoAnn Reff
*Southern Arizona - Robin Forsyth	*Asheville & WNC Region - Sharon Sayles
Greater Los Angeles - Janet Neal	*Piedmont Triad (NC) - Angie Smith
*Local Group of Greater San Diego - Mika Miller	*Southeastern NC - Ruth Brunick
*San Fernando Valley Group - Shari Gamson	*Angels of Abilene - Melissa Ragan
DC Area - Sheri Collins	*Dallas/Ft. Worth - Kim Wells
*Emerald Coast, FL - Sue Jenkins	*Greater Houston Group - Michele Hegler
Tampa Bay Group - Jody Guttridge	*Milwaukee - Nancy Reeling
*Looselinks (Atlanta) - Judy Sobel	*EDS Cyber Research Group - Liza Sauls
*Chicago Group - Janine Sabal	*York County EDS Group (ME) - Christine Klasner
Michiana - Leslie Rothe	*Baltimore - Shira Saperstein
*Staying Connected (KY) - Katrina Bate	St. Louis, MO - Lesley Gresham
*MidSouth (LA) - Charlotte Blocker	*Southern New Jersey - Cathy Bowen

Is it hard to get family members to participate in local group meetings?

By **Mika Miller, President, Local Group of Greater San Diego, EDNF**

Do you find that family members are not willing to attend your local group meetings? Are there spouses, children, friends or any other support personnel out there that are not attending your meetings? Have you ever asked why? As a group leader I wonder why? Where are those personally experienced and trained in the day to day living with EDS people? Why don't they "connect loosely" or otherwise? As a group leader I don't have a clue. As a person both living and suffering from EDS, I think I know.

They are there. They are behind us one way or another. They support us in our determination to attend our meetings. They encourage us to be independent. They are pleased when we return feeling satisfied having attended and given our time to our cause. But that is only one side of this two-sided coin. The other side is they may feel that they don't "belong" at our meetings. Indeed, their support of us daily may be just as much as they can give and attending these meetings, from their perspective, may be more than they can handle. But I ask you now to consider this; do you steer the direction of attending the monthly meeting so that you (consciously or subconsciously) go alone? Independently, selfishly, and purposefully, so that you can use this time to wind down, decompress?

There are many things that happen at our monthly meetings but first and foremost we bond. We give support, we complain, we share common aches and pains, tell stories of our all too familiar frustrations, but most of all we feel "normal" because everyone else there usually has experienced the same things. Could it be, and I ask you to mull this around a bit, that because we cannot fully share and participate in all the activities of our families

daily living, we feel the need to have a space (experience) that they too cannot fully share in?

Do not take this as an accusation, but take it as; what if? Think about it. I have. I feel very strong and supported at my local group meeting. I don't have to say, "No thanks, I can't make it, but I'll watch you do it (Insert in place of it: run, walk, hop, hike, skip, jump, lift, dig, etc). At my local meeting I participate as an equal with a common thread. Together we "connect" in our common cause. I say that I am just as guilty for my family not being there as I am for me attending.

What if our families attend? What could we personally benefit from this? How would our local group or even national benefit? First of all, we would have able-bodied participation. Excuse me for being blunt but we do need physically strong individual assistance in our lives. Why not in our groups? Also, if as a local group we are working hard to disseminate information and increase awareness in the community wouldn't we immediately double (at least) the manpower to spread this awareness if we brought along one family member and elicited their help in our cause? I say why stop at one? Many brothers, sisters, cousins, aunts and uncles to name a few would love to know how they could help us. Spreading the word, giving time, donations, and their services is just a start. Allow them to help - it feels good both ways.

From this moment on I will work towards educating my family and friends on how they can support my favorite cause, EDNF. May I dare suggest - consider this a challenge - to do the same at your next monthly meeting.

From the Director of Local Groups...continued from page 4

support to local groups and local group leaders also involves one of patience. But, in my vision of the perfect EDNF world, every member of the EDNF calls Andrew or contacts me and asks, "what can I do?" Every person involved in the EDNF knows and/or cares about someone with EDS or has it themselves. And everyone can help in some way, big or small.

The important thing is that we use our resources, do what we can, contribute in some way to making the lives of our loved ones, ourselves and those to come after us who must deal with EDS a little better. Andrew challenged me to help make this vision for the EDNF and people with Ehlers-Danlos syndrome a reality. Now, I challenge you to join us.

From Educating to Fundraising, a Local Group's Goals

By **Mika Miller, President, Local Group of Greater San Diego, EDNF**

I am so excited to finally have the ability to fundraise. But that is only a small part of what I see our group doing. We have written our Mission Statement and we coincidentally were right in line with the national mission. Although we are not as large as the national we can have as much impact.

Our number one mission is to provide accurate information. One way in which we will do this is by providing resources. I am very excited that with all of our help we will assemble as much educational and informational material as possible so that when a member needs it, or a new member wants to get "up to date" and informed they will use our portable reference library. Included in this library will be past issues of Loose Connections, medical articles, past conferences, ER CD, Parent / Teacher magazine and Educational Guide, brochures, our list of website references etc. The ability to offer this information to members to review can and will alleviate many questions and much anxiety that new members searching for answers and hope often feel. (Editor's note: and now all this information can be posted on the main www.ednf.org on the group's home page for everyone to see.)

But this is only a small part of what we can do. Along with our goal of providing information comes the need to increase awareness of EDS in the community. I see this mission as a strong second. How can we increase awareness? We live our daily lives increasing the awareness of EDS. The only thing we now need to do is add the conscious effort of recognizing when we have opportunities to raise awareness. In other words, actively communicate and participate both within our group and the community.

Now don't panic, I don't mean public speaking (but if you feel up to it, knock your socks off!) No seriously, what I'm referring to is letting others know who you are, what you're about, why you do what you do, what role EDS plays in your life, how you manage EDS, how you intend to fight EDS, how you and they can help EDS and of course bottom line, how their participation in our local group, whether monetarily, with goods or their time and attendance can help. You see, the more

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Support and Communication

The Ehlers-Danlos National Foundation Contact Database

If you have not yet signed up for your free access to the members area at www.ednf.org, then now is most certainly the time. One of the features that is growing in popularity is the contact database. To date several hundred members have entered their information; ranging from geographical location to type of surgery, the contact database is the fastest way of identifying an individual member who may be able to help you.

As with everything within the EDNF, the success or failure of the contact database is 100% dependent upon YOU the member, inputting their information. If you choose not to partici-

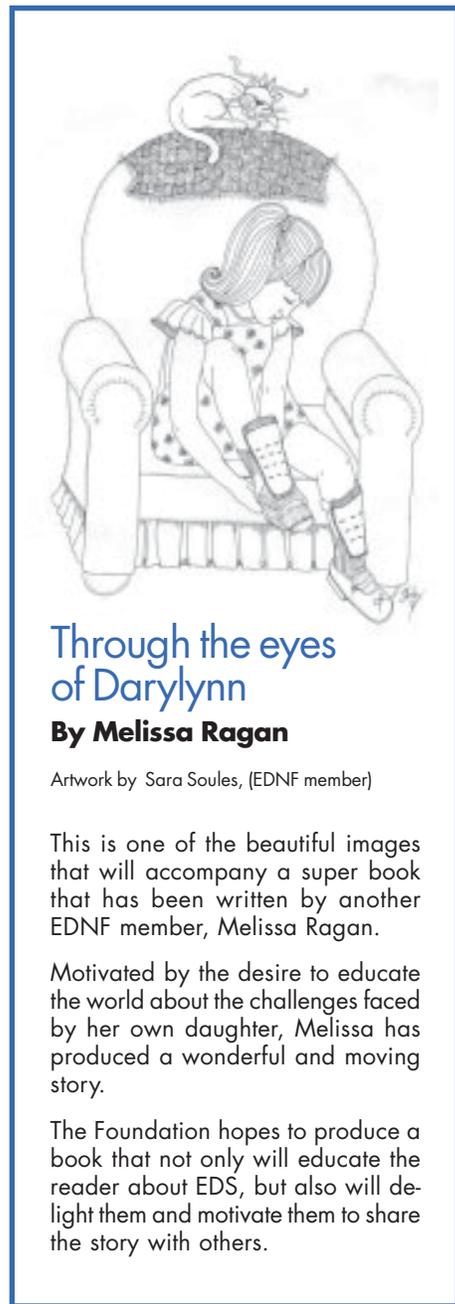
pate then how can you expect anybody else to?

The Ehlers-Danlos National Foundation does not lend, sell or trade its membership list or its members details to any individual or organization. This system is only accessible to EDNF members by use of their login name and password. No one else has access to the secure members area. Information stored on this database is more secure than the physical paper copies that are kept in the national office.

If you do not yet have a login and password to the member's area, either send an e-mail to memberservices@ednf.org or send us a letter with the following information:

Login Name – Choice 1		Password
Login Name – Choice 2		Password must be between 4 & 9
Login Name – Choice 3		characters, letters and numbers only.

With over 1350 families now with active accounts, we need you to give us several options for your login as the most obvious ones have already been taken.



Through the eyes of Daryllynn

By **Melissa Ragan**

Artwork by Sara Soules, (EDNF member)

This is one of the beautiful images that will accompany a super book that has been written by another EDNF member, Melissa Ragan.

Motivated by the desire to educate the world about the challenges faced by her own daughter, Melissa has produced a wonderful and moving story.

The Foundation hopes to produce a book that not only will educate the reader about EDS, but also will delight them and motivate them to share the story with others.

Free Children's Camp Opportunity, Summer 2004

The Children's Skin Disease Foundation <http://www.csdf.org/> in partnership with Paul Newman's organization, The Painted Turtle, <http://www.thepaintedturtle.org/turtle/Camp.asp> is offering opportunities for children between the ages of 7 and 17 years to attend camp this summer.

To quote from the Painted Turtle: "The Painted Turtle will provide a meaningful, medically safe camp experience for children ages 7 to 16 at

no cost to the child or his or her family" There are two opportunities this year; on the west coast at the brand new camp in Malibu, California between 1st & 7th of July and also in North Carolina between 17th & 23rd of July.

If you would like to find out more or request an application, please get in touch with Christine Tenconi at the CSDF

E-mail: ctenconi@hotmail.com
Tel: (925) 947 3825

2004 Learning Conference Update

The Ehlers-Danlos Learning Conference 2004, will be hosted by the Western New York Group and held on July 15 - 18, at the beautiful Hyatt Regency in Buffalo, NY. A dedicated issue of Loose Connections will be ready in the next two weeks and will contain all information pertinent to the conference.

If you can't wait for the conference information to arrive and would like to book on-line, the Hyatt has set up a web page specifically for people to register for the EDNF conference. To find out more, please click on the link below:

<http://buffalo.hyatt.com/groupbooking/ednf>

You can also contact the Hyatt at:
1-800-233-1234

If you experience any problems, you may call the Buffalo Hyatt direct at
1-716-855-4940

My name is Jimena Casanova and this is my story...

I live and grew up in Mexico City, I am 26 years old and looking forward to getting married next year and for the past ten years or so I have come to meet more than 30 specialist in hands, joints, nerves and even genetics, but every single one of them had more questions than answers to give.

You may not understand the point of this story, so I better start from the beginning, ten years ago...

It was the summer of 1994, I was three months short of turning 16, when I discovered a small lump in the center of the back of my right hand, I never gave it a second thought, I just thought I had hit my self with something, it was not painful. By December of that year I noticed the lump had grown and it started to be painful, I also got cramps in my hand more than once a day. The next day I went to a doctor and I was diagnosed with having a small ganglarian cyst.

The doctors scheduled a surgery that week, after that I thought the problem was over. I was wrong it was just the beginning of a long journey between doctors, wrong diagnoses, dead ends and not to mention unanswered questions.

I came back to Mexico with the confidence that I was cured and I just went on with my life, but my confidence was short lived; the pain came back stronger than ever, as well as the cramps that sometimes paralyzed my right hand. My left hand was normal. Immobilization seemed to do the trick, so cast and splints became part of my every day life, as well as pain killers.

All that year I was treated by a doctor in Mexico, Dr. Carlos Gargollo, and after exhausting tests, he came to the conclusion I had Kienbock Disease. As I learned more and more about this illness my concern and my parents concern grew and we found one of the main researchers of the disease, Dr. Andrew Weiland in New York City. I was there within a week. He gave me relief, he told me I did not have Kienbock Disease, instead I had another ganglarian cyst, but this one was much bigger than the last one, it was almost as big as my hand. Once again I faced surgery; once again I came back to Mexico and found pain. Dr. Weiland treated me for a couple of years and at the end he handed me a letter telling me he was lost.

By this time I was tired of doctors, casts, splints and all the things that were happening to me, I stopped looking for answers. But the pain never left, I learned how to live with it, trying every day to forget the fear of what is unknown and what may happen. I developed

this system which I call the Scale, what it does is that it helps me to manage the painkillers that I take every day, I am used to a level five or a low six of pain.

A few months later things got worst, my fingers started to dislocate, my thumb and small finger in my right hand were constantly out of place. I decided it was time to start a new search, this time I was determined not to rest till I had an answer.

I went to Dr. Fortunato Reyes, he was the one who put the cast on my hand every time pain got to a level where painkillers were obsolete. He suggested another surgery; he would shorten my tendons making my fingers stay in place. In Spring Break of 1997 I had surgery, three weeks later my fingers were dislocated again. Amazed Dr. Reyes told me he was also lost and that he could not longer help me, except to put the casts on. He then recommended me to Dr. Kliener in Louisville, Kentucky.

Dr. Kliener was the first one to mention Ehlers-Danlos Syndrome (EDS). He noticed I could stretch my fingers backwards till they almost touched the back of my hands, I could do that for as long as I can remember, but I never saw it as having joint problems, just as a cool trick I could do with my hands. He suggested a fusion of my dislocating fingers.

I came back to Mexico with doubts on my mind, I knew I had to make a decision, but I was scared. After sometime the everyday pain made me come to a conclusion. I went for a second opinion.

I waited till my school year was over and during the summer I went to Houston, Texas. There I went to see Dr. David Hildreth. To my surprise he gave me the same diagnosis and solution as Dr. Kliener. So in the summer of 1998 I had my first profitable surgery, the fusion of my small finger and my thumb. The pain went away in those areas but still I looked for an answer, because when I thought my quest was finally over, my thumb in my left hand dislocated and the pain came with it. A few months later my middle finger in my right hand and finally my elbows started to hurt and pop.

That same year I went to see Dr. Carlos Baccino, a geneticist, he conducted a biopsy which showed that I don't have EDS type IV, but it is very likely I have type I or II, because of an abnormality in the chains of collagen type V.

I returned to Mexico and to college, but it was hard to explain to teachers a problem you couldn't see. Two years passed and I de-

Dear Charlotte,

Kim Bishop and I met with Andrea Collins PR for GA Arthritis Foundation. We explained the various types of EDS, gave her a bunch of materials and asked her share it with all the staff members. She was very impressed with the new materials and promised to review them with the people who give phone information.

Kim asked about fundraising as a joint project and got a positive response as well as a name to follow up with.

I suggested the project of asking doctors to put chair exercise tapes in their waiting rooms. Arthritis foundation has these tapes that sell for \$10-15. I think she really liked the idea and said that she would talk with her supervisor about the possibilities of writing a grant to fund such a project.

She told us she would include information about EDS in their next newsletter, which has not been sent for some time because of lack of funds. They are starting it up again in a few months. But the best information she shared was that she would contact us about local free health fairs around the state. If we could put together a poster and give out booklets at local health fairs, it would be a super way of advertising EDNF and the Atlanta Chapter.

All in all, it was a very informative meeting. Both Kim and I came out with a list of things to follow up with.

Judy Sobel, President Atlanta

decided to finish school in the United States. By the end of college I had come to terms with my condition and with the idea of never knowing for sure. My doctors visits just became check ups, I had given up on finding a cure.

Then on November of last year I slammed my little finger on a car door, the screw holding it in place was loose and my finger was dislocated, again. But not all bad ends up bad!, when I went to Dr. Hildreth for a solution, he gave me back the hope I had lost. A possible solution for my dislocating joints: joint replacement. So at the beginning of this year I went for another surgery, I'm still recuperating but my hopes are up, in two weeks the cast will come off and I will be able to bend my little finger with out pain or dislocation.

I have tried to make this letter short; the doctors I mention are just the most important of a long list that finds no end. I have come a long

continued on page 14

Fostering and Supporting Research

Call for Samples

Project: Human Genetic Cell Repository

Project Sponsor: National Institute of General Medical Sciences

Principal Investigator: Donald L. Coppock, Ph.D., Coriell Institute for Medical Research

Goals: The NIGMS Human Genetic Cell Repository is a repository of cell lines designated specifically for distribution to the scientific community. The Repository was established at Coriell in 1972 by the National Institutes of Health and serves as source of cell lines that are of high quality, verified, and characterized and are available for distribution to all qualified scientists. Currently, the repository has more than 8,500 cell lines. The major focus of the Repository is on providing resources for scientists who study inherited diseases. Almost 100,000 cell lines and 250,000 DNA samples have been distributed to scientists world wide. More information about Coriell is available at: <http://locus.umdj.edu/>. We want to expand our collection of samples from Ehlers-Danlos patients and their families. In order to serve the research community better, we need many samples from all types of Ehlers-Danlos Syndrome.

Importance of the project to Ehlers-Danlos Syndrome patients: Since it is so difficult for researchers to contact patients and their families to establish cell lines for research, a central repository is an important resource for all researchers of Ehlers-Danlos Syndrome and related disorders. The materials in the NIGMS Human Genetic Cell Repository will be available to *all* qualified researchers worldwide.

Who can contribute? We urge all Ehlers-Danlos

Syndrome patients and their first-degree relatives (parents, siblings, children) to submit samples.

What kind of sample? From all involved in the study we need a blood sample from which we will prepare a lymphocyte line. In addition, if possible, we need a biopsy from which a fibroblast line can be established. It is important that detailed clinical data accompany the sample. Please call to arrange to obtain an appropriate sample collection kit.

Cost of participating? There is no cost to participate.

How do I proceed? Contact Coriell at the addresses below and we will send you or your physician a sample collection kit. The kit will contain all tubes needed for the collection you have arranged. It will also contain the Submission Sheet for the sample description and clinical data, a consent form (if needed) as well as a Fedex Prepaid Return Label.

Contacts:
Barbara Frederick
Senior Data Manager
Coriell Institute for Medical Research
403 Haddon Ave., Camden, NJ 08103
856-757-9690
bfrederi@cimr.umdj.edu

Donald Coppock, Ph.D.
Principal Investigator, NIGMS Repository
Coriell Institute for Medical Research
403 Haddon Ave., Camden, NJ 08103
856-757-9741
dcoppock@cimr.umdj.edu

EDNF Cyber Research Group

As part of our ongoing strategy of empowering our membership to get involved, we would like to make people aware of the work currently being undertaken by Liza Sauls, leader of the EDNF Cyber research Group. This is the group's mission statement:

"Our goal is to enable the EDS patient to participate in gathering data and research, regardless of their geographical location. With this data, we can facilitate further research, leading to better diagnosis and treatment protocols."

Over the next few months Liza and her team of volunteers will be presenting an on-line survey that we hope you will participate in. The survey is being written at the moment and is receiving input from established physicians and epidemiological experts in order to produce the most valid data available from a non-clinical exercise. Look for more information at www.ednf.org and in the next issue of Loose Connections.



"Patch Kit"

By Noah Baerman
Now Available Directly From www.ednf.org

Noah Baerman makes a powerful statement with his new trio album "Patch Kit," featuring the all-star rhythm section of bassist Ron Carter and drummer Ben Riley. It is not only passionate jazz from a soulful and mature young pianist, but also the transformation of a negative situation into a positive one. In the midst of his struggles with Ehlers-Danlos Syndrome (EDS), Noah produced "Patch Kit" as a way to raise awareness of this serious but little-known condition. 100% of the proceeds go to the Ehlers-Danlos National Foundation. Patch Kit sells for \$15.00 + shipping and handling and you can buy it straight off the EDNF website using your credit card through the new secure shopping cart.

Patch Kit is now being actively promoted to jazz radio stations all across the country. Check out the EDNF website for a full list - and please - phone up your local station and find out whether they have it - every spin increases the awareness of EDS and will result in greater sales.

**In memory of Amber Jevcak,
Ryan Haneline and Sheila Hanft**
Northeast Ohio Branch of EDNF

In honor of Melissa Regas
Frank & Mary Cuenca

In memory of Ryan Haneline
William L. Costello
Sunburst Races Memorial Health &
Lifestyle Center

In memory of Tham Meyers
Lake Park Social Club

In memory of Thomas Badik
Pamela Badik

In memory of Wilhelm Huber
Frieda & Wilhelm Huber

In honor of Jonathan Corn
Kimberly Dickey
Amy Corn
Jane Shaw

In honor of Noah Baerman's CD
Erin Wiswell
United Way Chicago Area Camp
Kelly Hamer

In honor of Glenn D. Ross
Barbara E. Keddy*

In memory of Robert Renert
Linda C. Hamlin

**In memory of Judith Simmons
Dion, Lisa Dion, Pickford,
Michelle Dion & Roger Pickford Jr.**
Nancy Sue Penn
Susan E. Dion
Natalie F. Birrell

In honor of Jonathan Corn
Karen Kurokawa

**In honor of Josh Rosenheck's 30th
birthday**
Maureen Kurtz

In honor of Lynn Sanders
Sandra T. Repinski

In honor of Meredith Jaster
Vera Jaster

In honor of the Lavallee Family
Molly Rush

In memory of Adam Cline
A-Ba-Ja's Inc.

**In memory of Dennis Youngblood
and Ron and Shirley Anderson
(grandparents)**
Margaret Leggett

In memory of Gabriel Anderson
Michael Belli

**In memory of Jacob "Jack"
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Savannah Lodge 1550

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chp.1361

In memory of Lester London
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2003 Read-A-Thon
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Dianne M. Hale
Ronald Goldberg
Vincent S. Lamia
Laura A. Leeming
Carol A. Klyber

In honor of Elyse Smith's birthday
Karen Kaufman

In honor of granddaughter Nikki
Joan Jackson

**In honor of Julia Parks/
Everett Parks II**
Susan B. Tiemann

In honor of Meg Harmon
Kay Johnson

In honor of Noah Baerman's CD
Stephen Bloch
Kathryn J. TenEyck
Noah Baerman
Pi-Hsun Shih
Christopher Dingman

**In honor of Susan Alden Maggie
Buckley**
Karl Brown

In memory of April Leaman
Tina Leaman

In memory of Gertrude Polowitzer
Giacomo Tedone
Dolores & Dominic Fusco
Jean Kravsow

In memory of Robert Renert
Lauren & Paul Bogart

**In memory of Robert Renert & In
honor of Glenn Ross**
Hilda & Lance Pursner

In memory of Ryan M. Heneline
Edward P. Horvath

**In memory of Sara Goldstein,
Marni Goldstein White,
Callie Goldstein &
In honor of Harold Goldstein**
Murray L. Nathan

In memory of Shelia Trapp
Jeff H. Campbell

continued on next page

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Dissemination of Accurate Information

So what is “Branding?”

By Andrew McCluskey

This issue of Loose Connections marks the end of the branding process that was begun back in September last year. Over the last few months we have applied this new look to everything that we produce: Emergency Room CD-ROM, Information Leaflets, Educator’s and Parent’s Guide, Web Site, Letterhead, etc.

A branding exercise is more than just a new logo, a color scheme or a typeface. The term “Brand” covers our total personality and encompasses the broad range of issues we need to consider when we communicate.

A visual representation of our reputation, our identity must be kept consistent across all our communications in order to be recognized, remembered and rewarded with trust. It is critical that we are seen to look and act with a single united voice and image. So what does all this mean?

Above is what we call the Master Logo; this is the “touchstone” of our visual brand. Along



with our name, it forms the one consistent element throughout our communication material. The logo is made up of two elements; the EDNF symbol and the EDNF word mark. Both elements have been carefully designed and their relationship is fixed.

So how did Jackie Hay, (the consultant that managed the project) and her team arrive at the final look? They spent several weeks looking at the EDNF; the history of the foundation, the nature of the syndrome, how our members communicated through the web site and what plans we had for the future. They were very careful to preserve the caring nature of the foundation but also to ensure we presented ourselves in a professional but approachable manner.

Please note that logo design is always easy in hindsight! The simplest things are often the hardest to get right. The design concept is that of two hands holding a bright light, the ushering in of “A brighter day”. By “squaring” off the image, we adopt a more professional and cleaner look, while still retaining that “light at the end of the tunnel”.

Now let’s have a look at how the words Ehlers-Danlos NATIONAL FOUNDATION are presented. Those of you who are familiar with word processors will be aware of the myriad of different fonts that are currently available. In a similar fashion to how a logo can describe the personality of an organization, the choice of font is equally important. We have chosen to use Futura (which is what you are currently reading) for all printed material and Arial for all Digital material.

These fonts have been adopted because they look familiar, they are easy to read, but they are a little different from the standard Times New Roman or Courier – in their lowercase the fonts are warm and approachable, and yet in caps they are formal and professional.

In summary, our Master Logo is our picture of who we are and how we see ourselves in the future. Branding experts talk about an organization’s Brand Values. With this new look applied to every piece of media that we produce, we show the world that the EDNF is Professional, Approachable and Smart.

Ehlers-Danlos Syndrome Discussed in California State Senate Hearing

By Maggie Buckley

Those of us living with EDS know firsthand that pain is a major issue in daily life. Since we are affected by an obscure disorder with a difficult-to-pronounce name and a complicated montage of symptoms, we find it difficult to communicate our circumstances to doctors. Let’s face it, we wish the doctors knew more or somebody else could explain it to them for a change. Some of us even catch ourselves thinking: “There ought to be a law that the doctor must listen to me describe my pain and do something about it!” Thankfully, some State Senators, doctors, researchers, and patient advocates agreed to take it to the California State Capitol Building.

In late January 2004, the California State Legislature designated February as Women in Pain Awareness Month. Wednesday, February 4, was a clear bright day in Sacramento, California, not just because of the fine weather, but because Ehlers-Danlos Syndrome was discussed during a hearing on Pain. I had been invited to speak about the under-diagnosis of Ehlers-Danlos Syndrome and the consequences of a missed or late diagnosis. Also, I was

asked to talk about what type of support infrastructure addresses those with EDS. In addition, organizers requested that I share my experience working to raise awareness of EDS and educate women pain patients on how to work with their physicians.

The hearing on February 4 was an informational hearing to further explore the topic of Women in Pain. It was organized in coordination with the California Legislative Women’s Caucus in an attempt to gain a more thorough understanding of the issues surrounding under diagnosis of chronic pain and the role of gender in the under treatment of pain. There was also the question of whether or not there might be a legislative remedy to this problem.

Co-chairs of the hearing were Senator Debora V. Ortiz, Senator Liz Figueroa, and Senator Nell Soto. Senator Figueroa began the hearing by welcoming the panels of speakers and by introducing the issue of Women in Pain. Senator Soto’s opening remarks included the announcement that Senate Concurrent Resolution No. 42 had indeed been passed, offi-

cially designating February as Women in Pain Awareness Month.

The first panel of speakers sought to frame the issue with personal stories and academic research. Ms. Cynthia Toussaint, the founder of For Grace (www.forgrace.org) shared her personal story of learning to live with Reflex Sympathetic Dystrophy and the journey which had brought all of us to that hearing room. (A copy of Ms. Toussaint’s testimony is available at www.ednf.org) The validity of the topic was reinforced by academic research presented by Professor Diane Hoffmann, Associate Dean at the University of Maryland School of Law. Dr. Hoffmann is co-author of “The Girl Who Cried Pain: A Bias Against Women in the Treatment of Pain” which was first published in the Journal of Law, Medicine & Ethics in 2001.

The second panel of speakers was charged with presenting the Patient and Advocacy Perspective. Ms. Susan Matsuko Shinagawa of the Intercultural Cancer Council shared her personal story as a breast cancer survivor

continued on next page

Dissemination of Accurate Information

Ehlers-Danlos Syndrome Discussed in California State Senate Hearing...continued from page 11

and chronic pain patient. Ms. Shinagawa's story moved almost everyone in the room to tears. As the second member of this panel, I explained EDS with an emphasis on the importance of pain as a diagnostic criterion for a little understood disorder. I also talked about some tips for improving the communication of pain to doctors. Additionally, I presented brief overviews of the types of support organizations that are targeted to those with EDS. (A copy of my testimony will be available shortly at www.ednf.org.) The third speaker in this panel was Dr. Kathryn Padgett of the American Academy of Pain Management. Dr. Padgett, who shared statistical information on the under treatment of chronic pain, emphasized that prescription opioids AND a multidisciplinary approach provide much needed relief for individuals suffering pain. (A copy of Dr. Padgett's will also be available at www.ednf.org.)

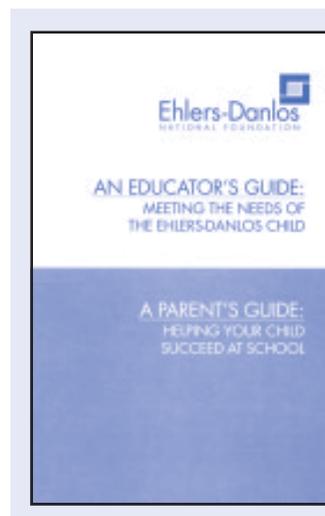
The final panel provided a thorough response from the medical community. Dr. Steven Richeimer, Director, USC Pain Management, USC Medical Center, spoke about treatment protocols. Ms. Sally A. Adelus, RN, Executive Director of Hospice in the Valley in Santa Clara County, shared examples of the types of treatment she has witnessed for pain patients. Please note that one of the patients she spoke about was an EDS patient. Dr. Scott Fishman, Chief of the Division of Pain Medicine at the UC Davis Medical Center also spoke about treatment protocols and gave examples of how patients fared in a variety of circumstances. Finally, Diana Adams EdD, Adjunct Clinical Assistant Professor, Department of Psychiatry and Behavioral Sciences at Stanford University Medical School, presented some of the history behind pain terminology and treatments. All of the speakers in this group illustrated that there are compassionate doctors out there who know a great deal about this subject and reinforced the point

that there is still much to learn about pain.

Many thanks go out to Stayce Curry for her impressive efforts to spread the word about this hearing in California. As a result, hundreds of letters, emails, and phone calls were received by our Senators and Assembly members making them aware of the hearing. Thus, six Senators and two Assembly members attended the hearing on February 4. This is remarkable because an informational hearing such as this is typically sparsely attended. By making their voices heard, our members let their Senator/Assembly member know that this was an important issue to their constituents. Present were Senator Liz Figueroa, Senator Nell Soto, Senator Sheila Kuehl, Senator Edward Vincent, Senator Wesley Chesbro, Senator Richard Alarcon, Assembly member Patty Berg, and Assemblywoman Gloria Negrete McLeod. In addition, the audience gallery was completely full. Thank you to Stayce Curry and all of our California members who let their Representatives in Sacramento know that this was an important issue for them to learn

about.

Members of EDNF have learned that having our voices heard by our elected officials is a key to improving the quality of our lives. Prior efforts by our members resulted in Meg Harmon's testimony at a US Senate Health and Human Services Committee Hearing in April of 1999. As a result of that testimony, coupled with prior and subsequent lobbying, the number of NIH research projects encompassing Ehlers-Danlos Syndrome significantly increased. Now, just as then, there are many members working to keep EDS on the minds of legislators. Thankfully, we were given the chance to do that in California in February 2004. It is hoped that as a direct result of this hearing, there will be changes in the certification and/or continuing education requirement of healthcare professionals relating specifically to effective treatment of pain patients. Look for more information in future issues of Loose Connections and on the website (www.ednf.org) in the coming months to see where we go from here.



By Peggy Rocha Snuggs Director at Large for Children's Projects & Education

The Ehlers-Danlos National Foundation is pleased to present our newest publication entitled: "An Educator's Guide: Meeting the Needs of the Ehlers-Danlos Child, A Parent's Guide: Helping Your Child Succeed At School." This publication has been prepared to help the educator better understand and provide for the needs of the school-age EDS child, and to help parents better understand some of the options that are available to promote their child's academic success.

To date we have distributed over 2,500 copies of the guide. If you would like to obtain a copy, please contact the national office or send an email to: memberservices@ednf.org.

From Educating to Fundraising, a Local Group's Goals...continued from page 5

we share with the community what we EDS sufferers go through, the more we increase their awareness and the less foreign a "thing" EDS is. Then they are more willing to look at EDS, understand EDS, and do something about EDS.

I always use this example; think back to the first time you heard, MD. You probably thought, "What's that"? Or, you heard the term, muscular dystrophy, again you may have thought, "I can't even say it let alone know what it is". Now think of today; what do you think, know and understand when you hear MD, muscular dystrophy, "Jerry's Kids", the Labor Day telethon? You see? Why do you know so much now? Because people began

to share and communicate. They got the information out into the community, shared their stories and raised the awareness.

This is why I am so excited; we can all do this daily, in our lives. We work, shop, attend places of worship, schools, sporting events, and clubs. Everyday is an opportunity to give the community a chance to learn about EDS. We are the best representatives of EDS. Granted we have an investment in EDS, but we also have a passion and with this passion we can "turn on" others to our shared cause. Once we have others passionate about our cause they too will increase awareness within their communities. And so the awareness and knowledge grows and the helping and giving

begins. Which leads me right back to my original statement and the ability to raise funds.

Education and awareness go hand in hand with fundraising, if you take all available opportunities to share the vast knowledge you have of life with EDS, the fundraising will happen. With knowledge comes power and people will do what they can for your organization if they have the knowledge of who and what you are. If we begin by comforting and reassuring those with questions, educating and raising the awareness of those in our community in need of answers, then our actions will guide others in the community who want to help to give donations and support to us.

Informational Hearing of the Senate Health and Human Services Committee

Senator Deborah V. Ortiz, Chair

Women in Pain: Trends and Implications of Underdiagnosis of Chronic Pain in Female Patients

Wednesday, February 4, 2004 • 1:30p.m. to 4:00p.m. • State Capitol, Room 3191

Background

Extensive research has been done to examine the reasons for inadequate treatment of chronic pain in the United States, but more recent studies have begun to look at whether women pain patients face an additional barrier to proper treatment and diagnosis. A 2001 study in the *Journal of Law, Medicine, and Ethics* entitled, "The Girl Who Cried Pain: A Bias Against Women in the Treatment of Pain," found that "women's pain reports are taken less seriously than men's, and women receive less aggressive treatment than men for their pain." This background paper will outline the biological, psychological, and cultural gender differences that affect the service provision, diagnosis, and adequacy of treatment. In addition, this paper will outline several of the chronic pain disorders that affect female patients.

Approximately half of all existing studies prior to 1997 found no differences between men and women in responses to pain, yet the studies that did report gender variations in pain experience cited the following factors in explanation of differences: lower pain thresholds, higher pain ratings, and lower pain tolerance for women. Early findings suggest biological differences appear to influence pain. For example, reproductive hormones influence women's pain, as sensitivity increases and decreases throughout her menstrual cycle. Studies have also shown differences in the brain and central nervous system in men and women, as well as in the ability of male and female rats to not experience pain in extremely stressful situations. A 1999 study by E.A. Mayer in the *Alimentary Pharmacology and Therapeutics*, using stimulation models and brain imaging techniques, found biological gender differences in the experience of pain related to irritable bowel syndrome.

Factors Affecting Gender Difference in Pain Experience

While biology may show gender differences in how individuals experience pain, emotional and cultural differences also play a role in how pain is experienced. For example:

Women routinely experience natural biological pain related to the reproductive cycle, in addition to pain accompanying disease or injury, therefore women may learn to sort their pain, whereas men do not.

Women also tend to describe their pain more in relation to how that pain impacts personal relationships, while men's reports more likely relate to functional limitations.

Behavioral characteristics of coping with stress also vary between men and women, with women being more likely to express feelings and seek support from friends and family.

Emotion and Pain. Children begin to learn how to react to painful events at a very young age, for example in some cultures boys are discouraged from showing emotion. Research has shown that baby boys are more emotionally expressive than baby girls are, but by elementary school boys have started to hide their emotions and are less likely to express pain or anguish. Differences in socialization may influence methods of communication, including how pain is discussed with a medical professional. Women tend to be more open to describing their pain, and use examples of the pain impact on their personal relationships.

Bias in Perception of Pain. Research also shows that medical providers respond differently to pain for women and men. A study of pain medication prescribed following abdominal surgery found doctors giving less pain medication to women. A decision of the World Health Organization to develop guidelines regarding prescription of painkillers was based on reports showing female AIDS and Cancer patients were less likely to receive pain medication. One study showed that women patients with chest pain were less likely than men to be admitted to the hospital.

Some researchers attribute the difference to the "Yentl Syndrome," that women have to prove that they are as sick as a man before receiving proper treatment, and that women experience obstacles such as disbelief at initial visits. A study of 300 nurses found a majority of nurses believed women were more

tolerant of pain, less distressed by pain, and more likely to report pain. Researchers have also found that physicians view unattractive patients as in more pain, and tended to prescribe unattractive patients more pain medication. Attractive female patients, on the other hand, were more likely than unattractive females to be viewed as able to cope with pain.

Consequences for Treatment. Evidence indicates men and women do experience pain differently, but this evidence does not seem to support the differences in diagnosis and treatment experienced by pain patients. Women are more likely to report their pain, but less likely to have their pain adequately treated, they often have pain discounted as psychological or emotional, and therefore seen as not real. Studies have also shown that while men often delay their treatment, they receive a more aggressive response from their provider after they do seek treatment. Another study found that providers were more likely to prescribe aggressive treatment for men because "of the demands on their bread-winning roles."

There has been some speculation that disparity in treatment of pain results from women not being accurate reporters of their pain. However, a recently published study by the National Academy of Sciences concluded that a patient's subjective description of pain is an accurate indication of the degree of pain experienced. The data from the study, which divided 17 individuals into two groups of pain sensitive and less pain sensitive and examined the brain activity of each group, found that individuals can look at their own experience and report their pain accurately. Researchers hope that this study will prompt more physicians to be sympathetic to pain patients, as early diagnosis and treatment is vital in ensuring acute pain does not develop into chronic pain.

Advocates' Perspective. Feminist literature points to another cause of gender discrimination in pain management among the medical community, that is, "the inability of a male-dominated health care system to hear women's voices." Dr. Vicky Ratner, an or-

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thopedic surgeon and Founder of the Interstitial Cystitis (IC) Association, first experienced symptoms of IC when she was a medical student. Prior to her diagnosis, fourteen different physicians told her the problem was all in her head, and one physician advised her to quit medical school and get married.

"It is difficult for a woman to trust her own judgement when experts are telling her she's wrong, but it is absolutely crucial she do so," Dr. Ratner wrote in "Lightning Strikes Twice: Perils of the Patient as Woman," a 1992 article in the *Journal of Women's Health*. "The medical profession has been overwhelmingly male dominated, which means that for centuries male authority has been overriding female experience. Women have been well trained to trust this professional authority, but there's something drastically wrong when male physicians are so confident about telling women what is going on in their bodies and so ready to trivialize and negate their experience. This makes it especially necessary for women to learn to be aggressive patients. Women may be the best judge of their own symptoms – their lives may depend on it."

Chronic Conditions

Witnesses at the hearing, particularly on the patient panel, will discuss their experiences with chronic conditions that cause pain in early stages, but that are not diagnosed for a prolonged period due to gender bias in the understanding of pain. Described below are some of the conditions that will be addressed in the course of the hearing.

Ehlers-Danlos Syndrome. (EDS) is a heterogeneous group of heritable connective tissue disorders, characterized by articular (joint) hypermobility, skin elasticity and tissue fragility. Individuals with EDS have a defect in their connective tissue, which provides support to many body parts such as

the skin, muscles and ligaments. Defects in collagen, which normally adds strength and elasticity to connective tissue, results in fragile skin and unstable joints found in EDS. Symptoms include, but are not limited to, fragile skin that tears or bruises easily, unstable joints prone to frequent dislocations, debilitating musculoskeletal pain, and poor muscle tone. Of the 1 in 5,000 to 1 in 10,000 individuals living with EDS, only 5% are receiving proper diagnosis. It is estimated that over 1/3 of people with EDS are disabled and unable to work.

Fibromyalgia. (FM) is a chronic pain illness characterized by widespread musculoskeletal aches, pain and stiffness, soft tissue tenderness, general fatigue and sleep disturbances. The most common sites of pain include the neck, back, shoulders, pelvic girdle and hands, but can affect any body parts. It is estimated that approximately 3-6% of individuals in the United States has Fibromyalgia, with women being more likely to be affected. Fibromyalgia symptoms include, but are not limited to chronic pain in varying intensity, mental and physical fatigue, and an associated sleep disorder. Proper diagnosis requires doctors to rely on patient history, self-reported symptoms, and an accurate manual tender point examination based on the standardized ACR criteria. It is estimated that it takes approximately 5 years for a FM patient to receive an accurate diagnosis.

Interstitial Cystitis. (IC) is an inflammatory condition of the bladder wall. Symptoms, which are similar to an acute urinary tract infection, include severe urgency, frequency and pelvic pain. Urine cultures are negative and patients do not respond to antibiotics. IC affects over one million people in the U.S., 90% of whom are women. A lack of awareness and understanding within the medical community has left many patients misdiagnosed or underdiagnosed. Epidemi-

ology studies reveal that it takes on average 5-7 years to obtain a diagnosis. Patients are left to live with debilitating symptoms when no diagnosis is made. Suicide within this patient population has resulted from a resistance to treating severe non-malignant pain with opioid medication.

Reflex Sympathetic Dystrophy. (RSD) is a multi-symptom, multi-system syndrome usually affecting one or more extremities, but may affect virtually any part of the body. If left untreated, this debilitating chronic pain disease can leave sufferers confined to a wheelchair or bedridden. RSD symptoms include abnormal function of the sympathetic nervous system, swelling, movement disorder and changes in tissue growth. While it is unclear exactly what triggers RSD, a number of precipitating factors have been associated, including trauma, cervical spine or spinal cord disorders, infections and surgery. It is estimated that this disease afflicts between 1.5 and 6 million people in the United States, with women being three times more likely to be afflicted. Although RSD was clearly described by physicians over 125 years ago, and while pain medicine practitioners have made progress in diagnosing and treating RSD, it remains poorly understood and is often unrecognized by the medical community.

Primary sources for this background paper include:

"The Girl Who Cried Pain: A Bias Against Women in the Treatment of Pain," Diane E. Hoffman and Anita J. Tarzian, *Journal of Law, Medicine & Ethics* (2001)

"Neural Correlates of Interindividual Differences in the Subjective Experience of Pain," Robert Coghill, John G. McHaffie, and Yefen Yen, *Proceedings of the National Academy of Sciences of the United States of America*, vol. 100, no. 14 (July 8, 2003)

My name is Jimena Casanova...continued from page 7

way since this started and what I want now is not only to find a doctor who wants a challenge, a challenge to make life painless and to find a way to fight this syndrome, which for

many people is still unknown. I also want to give hope to those who may have the same problems as me; I will keep you posted on how my new joint turns out.

If you are interested in contacting me, my e-mail is jimenacasanova@netscape.net

EHLERS-DANLOS NATIONAL FOUNDATION
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The EDNF produces a range of educational media that is distributed free of charge to those who request it. Information leaflets, articles, multimedia programs, guides and newsletters are examples of the kind of programs that are available.



6399 Wilshire Blvd., Suite 200
Los Angeles, CA 90048-5705
Telephone: (323) 651-3038
Facsimile: (323) 651-1366
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EDNF members are now able to communicate directly with each other through the interactive members' area at www.ednf.org. With over 15,000 posts as of January 2004, EDNF members have built an extensive information repository on EDS and it is growing every day.

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To find out more about the Ehlers-Danlos National Foundation or to see if there is a Local Group in your area, please visit our easy to use web site at www.ednf.org