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THE HINGE
EDNF Monthly Update

MARCH 2007

COMMUNICATION ⚡ **COMMUNICATION** ⚡ **COMMUNICATION**

The Eyes Cannot See What the Mind Does Not Know

Educating the Health Care Community: Teaching the Doctors

Use the articles found in *Loose Connections* as well as those on-line to inform your doctor and other health care professionals. Remember, it is the task of each of us to gather the materials provided and share them. Make this a personal goal!

EDNF Initiates New Professional Advisory Network Electronic Newsletter

EDNF has sent out its first Professional Advisory Network Hinge to members of our PAN. This quarterly e-newsletter is designed for and by our PAN members for direct email distribution to members of the medical profession. Let your doctors know they can email STAFF@EDNF.ORG to receive this quarterly e-newsletter, designed specifically for the medical profession. Involve them in this special connection for doctors from EDNF and its PAN.

Sports Doctor Creates National Resource for Rare Collagen Disorder

The efforts of EDNF PAN Member Dr. Mark Lavallee were highlighted in a terrific article about Ehlers-Danlos Syndrome in the *South Bend Tribune*. Dr. Lavallee has put together a team of physicians that have learned to deal with EDS, including a cardiologist, orthopedic surgeon and physical therapist. Many patients travel from all over the country to be seen by Dr. Lavallee and his team. To read the full article [CLICK HERE](#).

“Loose Connections” Continues to Grow

Thanks to your contributions both literary and otherwise, *Loose Connections* continues to grow and improve in the upcoming Spring 2007 issue. The usual sixteen pages contain two more pages of articles than previous issues, and are joined by this year’s Annual Resource Fund, included as an insert. Our regular and supporting members receive their issue by mail. For our “Access Members,” the newsletter will be on the website by the end of the month. Read it on-line or download it to your computer.

We are delighted to announce that *Loose Connections* will expand to 20 pages for the summer issue, in part to cover this May’s EDS Awareness Month activities; and if readers continue to send in stories, reviews, columns and scientific reports at the rate we are receiving them, those extra pages will be permanent. The growth is because of you; your response has surpassed every hope and expectation. Congratulations everyone.

EDNF Message Boards

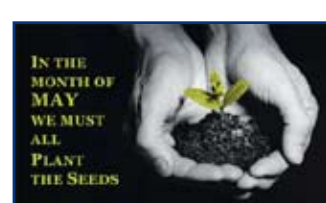
Our member only [MESSAGE BOARDS](#) have surpassed 45,000 messages. Who would have imagined that we could provide such a fantastic service to our members? A place where we can share our thoughts, express our concerns, and find support and friendship, more and more members are visiting our message boards than ever before, and we are thrilled to have each and every one of you.

Give Someone a Gift of Membership to EDNF

Membership has been growing and each additional member makes our voice stronger. Have you tried to encourage family members, community members and or medical professionals to gain a better understanding of Ehlers-Danlos syndrome? Consider giving a gift of [MEMBERSHIP](#).

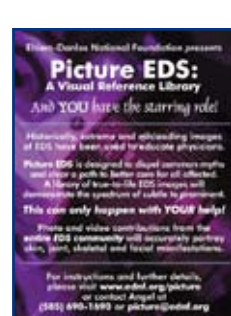
EDNF Reminds Everyone of EDS May Awareness Month

During the month of May help us educate the health care community as well as our friends and family. We have an ad available for [DOWNLOAD](#); use it to spread awareness of EDS however you can. There are many ways you can get involved! For a list of ideas visit our [AWARENESS BOARD](#) (be sure to check the whole page!) and please post any great idea you may have on our message boards.



Picture EDS: And YOU have the starring role!

Do your part in this worthwhile project. For more information click here.



Art Contest

“I Think Beautiful Is” is the theme of our 2nd Annual Art Contest that is concentrating on photography. This contest is open to people of all ages. Spread the word in your community by inviting scout troops, school classes, senior centers or college students to participate. You can download the [ANNOUNCEMENT AND ENTRY FORMS](#). The deadline for submissions is April 30, 2007.



Host an Awareness Display in YOUR neighborhood!

All you need to do is make some phone calls and reserve a space for one to two weeks and *EDNF Kids & Teens* will take care of the rest! We will send you a package containing 10-20 art entries (depending on your space) from our 2nd Annual Art Contest matted and ready to be displayed, along with posters that talk about Ehlers-Danlos. You just need to find a spot and set it up! Hospital lobbies, libraries, shopping centers or any area that gets local community traffic would be perfect. E-mail for more information MICHELEDARWIN@TX.RR.COM.

Called the EDNF Office Lately?

If you have called EDNF, you may have heard a new voice. It is the new voice of EDNF, Debbie Ignacio. She has taken Edzel’s position as one of EDNF’s two paid staffers, and has already weathered a crisis or two. When you e-mail us at STAFF@EDNF.ORG, Debbie may be the one answering you, and if you decide to call EDNF, please remember to make her feel part of the community no matter the reason for your call.

Website Issues

Should you have any website issues, please send your e-mail to STAFF@EDNF.ORG. EDNF is using fewer e-mail addresses through its site and has eliminated many of the past “help” addresses to simplify the website restructuring.

EDNF All-Types CD-Rom

This is an exceptional item to provide to your medical professionals. You can order a copy from [HTTP://SHOP.EDNF.ORG](http://SHOP.EDNF.ORG) and make your own copies for distribution. (You MUST include all the printed information with your copies of the CD.)

Educators Guide: Meeting the Needs of the EDS Child / Parents Guide: Helping Your Child Succeed at School

[ORDER OR DOWNLOAD](#) a copy of this one-volume guide to give to your school’s nurse, gym teacher and other school administrators.

Fundraising through American Express

Donations can be in earned points or monetary gifts for charities such as EDNF through the AmEx GivingExpress program. Click on the AmEx icon (right) or on the EDNF site. American Express is recognized worldwide, and anyone can donate, even if they do not have an American Express card.



Shopping through iGive benefits EDNF

Have you shared the iGive buying experience? Our joint efforts have earned EDNF thousands of dollars. To see all that iGive has to offer, visit through this link.



FirstGiving

Want to know a quick and easy and *ongoing* way that *YOU (and anyone you know) CAN HELP* support the programs of the EDNF without having to do much more than make a few clicks on your computer? Go to [HTTP://FIRSTGIVING.COM/EDNF](http://FIRSTGIVING.COM/EDNF) and it will only take a few minutes to create your own personalized online fundraising page. This is something everyone in your family may be interested in doing—spread the word! Honor a loved one, celebrate your birthday, raise sponsors for a walkathon, make a personal page for your friends and family to help support your sponsors and interests—you can customize your fundraising page however you wish. Visitors to your site can leave customized messages and their donations through your page are guaranteed secure. Go to [HTTP://FIRSTGIVING.COM/EDNF](http://FIRSTGIVING.COM/EDNF) and click the “Get Started” button. Once you have setup your very own webpage address, <http://firstgiving.com/yournamehere>, you can share this address with anyone and everyone you know! You can also tell them to get set up with this great opportunity as well—don’t keep this opportunity all to yourself!

Java Joe’s

Enjoy a great cup of coffee... and help EDNF!



Give Someone You Love Flowers Today!

When you order flowers at EDNF.FLOWERPETAL.COM, 12% of each purchase goes to EDNF. That’s \$6 for a \$50 purchase and \$12 for \$100. There are no additional fees for delivery—even same day delivery! And you can save up to \$10.95 compared to other online florists. So every purchase puts a smile on many faces—including yours!



Please send your comments as well as possible items for future Hinges to barbara.edsrc@charter.net. Items must be submitted for inclusion by the 10th of the month.

[REMOVE MY NAME FROM ALL FUTURE E-MAIL CORRESPONDENCE](#)

IF YOU ACCIDENTALLY REMOVE YOUR NAME FROM FUTURE MAILINGS, SEND AN E-MAIL TO staff@ednf.org WITH “RESUBSCRIBE” IN THE SUBJECT LINE.

Address-postal inquiries to:
Ehlers-Danlos National Foundation
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Los Angeles, CA 90010

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