



The NONF Newsletter

The National Osteonecrosis Foundation



NONF: A New Beginning

(A Letter from David Hungerford)

The NONF was founded in 1996 as a non-profit organization to bring together the needs of patients with osteonecrosis (ON), information about the disease and physicians with interest and expertise in the treatment of ON. Although we have had some successes, in the creation and distribution of an information pamphlet about ON, the creation of a web site for the Foundation (www.nonf.org) and a network of physicians as members of NONF and experts in the field, NONF has not yet reached its potential as an organization. Best estimates indicate that there are 10-20,000 new cases of ON each year. Since the disease occurs most commonly in the fourth decade of life (average age 38) and since it is not associated with reduced longevity in most instances, we estimate that there are in excess of 500,000 people alive today who have been afflicted with ON. While it is hard to be certain of the accuracy of these numbers, this is still a lot of people. Where are they and why is the membership of the NONF at least not in the thousands? We do not have a good answer to this question.

The majority of people with ON have only one or two joints involved. About 3% of cases

have multi-joint involvement. These are the people whose lives are changed forever as illustrated by Marie's Story (page 3). The most common operation for the majority of patient's with ON is a total hip replacement (THR). Fortunately, THR is highly successful at restoring the patient to full function. Although there may be some problem with THR in patients in their thirties as far as life-time longevity is concerned, most patients (even young ones) will get many years of symptom-free or low-symptom service from a THR. This category of patient may be less interested in joining an organization that is dedicated to education and research about a condition that is not a continuing problem for them. NONF was started by physicians, and with the exception of the past Executive Directors and the Secretary/Treasurer, Lynne Jones who is a PhD researcher in ON, has been directed by physicians. It turns out that this is not the formula for successful foundations focusing on a single disease such as the Lupus Foundation, or a particular organ system such as the Kidney Foundation. In fact the inspiration for the NONF came from Susan Stephanson, one of my patients with Ehlers-Danlos Syndrome. (continued on page 2)

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NONF Mission Statement

Today we are working at the frontier between what we know and what we need to know about osteonecrosis and Perthes' Disease. Osteonecrosis means death of bone. This results from a wide variety of conditions, many poorly understood, which lead to major joint damage in children and young adults.

Our goal is to provide much needed funding for medical research and education of patients, physicians, and other health professionals. To all participating physicians, we offer routine informational updates and patient educational support. To all Perthes children, we offer hope for early diagnosis and improved care. To all osteonecrosis patients, we offer hope for discovery of the causes of this debilitating disease and new effective forms of treatment. Through the combined efforts of patients, industry, and caring friends, we will succeed.

We Must Succeed!!!



Approximately 15-20,000 new patients are diagnosed with osteonecrosis each year in the United States. Since these patients have a normal life expectancy, there are an estimated 500,000 people living with this disease today.

NONF: A New Beginning

Ehlers-Danlos is named after the pair of doctors that first described the condition. Ehlers-Danlos is even more uncommon than ON, and there was even less information about it than there is about ON. Patients with Ehlers-Danlos Syndrome were at that time often misdiagnosed, resulting in inappropriate or unsuccessful surgeries that frustrated both patients and physicians. This patient, Susan Stephanson, decided to do something about it and started the Ehlers-Danlos Foundation, which today functions much as we hope the NONF will soon function. Susan has agreed to act as a consultant during this time of transition.

We are setting out to transform the Foundation. This will occur as volunteers assume a greater role in the organization. NONF has always been dedicated as a service FOR the patients. However it has been organized and directed by physicians. The transformation will result in an organization that is not only FOR the patient but also OF the patient and BY the patient. We believe that the way forward for the NONF consists of identifying, mobilizing and equipping volunteers to become involved in the organization. Our past executive directors have been volunteers. Marie Shanahan, the last executive director, has stepped down from the role to devote her full efforts to the patient advocacy web site and internet-based support group that she has so successfully pioneered, The ON/AVN Support Group International.

Research Review

According to the National Library of Medicine, there were at least 329 articles published in medical journals about osteonecrosis (ON) in 2004. Their topics are quite variable including articles on adult-onset and juvenile forms (Legg-Calve-Perthes), ON at different locations (hip, knee, talus, shoulder, spine, pelvis, jaw), and as a complication of other diseases and surgical procedures.

Although a majority of the articles were clinical studies, case reports, and reviews, there were 26 basic science articles. This represents an increase in the number of studies that are dedicated to increasing our understanding of the disease and its diagnosis and treatment. There were several outstanding articles published in 2004 which may ultimately impact on the prevention and treatment of ON. Some examples include:

- A Marshall R. Urist awarded article on whether there is a genetic predisposition for the disease (Zalavras et al., Clin Orthop, May 2004).

She will remain on the Board as a special consultant, and her internet-based support group will continue to work cooperatively with the organization.

We are currently without an executive director. Nonetheless, we continue to do what the foundation has done in the past, providing information to patients and physicians. In addition to executive director, we need volunteers at all levels, patient recruitment, grant writing, fundraising, web development. If you have time and interest, we can probably find something for you to do.

The old goals of the NONF remain valid. This transition represents new and renewed efforts to achieve those goals and add new ones, in line with the needs of our members. Ultimately, the Foundation aspires to influence the pace of discovery into the causes of ON and to put patients in touch with specialists who can offer the best possible current treatments, and who are involved in pushing back the frontiers of knowledge so that better prevention and treatment methods are available in the future. Everyone who has a desire to participate in the growth of our foundation is welcome. Participation can take many forms, and this will be the subject of future communications from the NONF to you, its members.

Sincerely,

David S. Hungerford, MD
Founder, NONF

- An evaluation of use of Autologous (self-donated) bone-marrow cells in the treatment of ON (Gangji et al., JBJS, June, 2004).
- An investigation on whether pain predicts outcome in ON hips (pain in early stages does not) (Belmar et al., Clin Orthop, Aug, 2004).
- A report of a Multicenter study of patients with Legg-Calve-Perthes disease (Herring et al., JBJS, Oct, 2004).
- A laboratory study of the effects of an anti-coagulant and a lipid-lowering agent on the development of ON (Motomura et al., Arthritis Rheuma, Oct, 2004).
- A study of the effect of a drug called alendronate in the treatment of ON (Agarwala et al., Rheumatology, Nov, 2004).
- A comparison of two surgical treatments (surface arthroplasty, metal-on-metal resurfacing) for hip ON (Beule et al., J Arthroplasty, Dec, 2004).
- A study of the use of bone morphogenetic protein (BMP) with core decompression (Lieberman et al., Clin Orthop, Dec, 2004).

(continued on page 3)

- A basic science study evaluating differences between different types of corticosteroids and the development of ON (Miyanishi et al., Rheumatol, Dec, 2004).

It is important for us to not only be aware of the results of cutting edge clinical and basic science research but also to understand these within the context of what is already known. Look for this spot in future newsletters to stay in touch with the most recent advances in ON research.



Marie's Story

Until the fall of 1994, I was a busy wife, mother, and medical office manager. Life was often hectic and as I raced through each day, never did the concept of long-term chronic illness enter my mind. That was something that always happened to other people, not to me. As I locked up the office at the end of each day, bidding goodnight to the last patient and my boss, I'd head for home, happy with excitement at seeing my husband, family and friends once again. Living in the so-called fast lane of suburbia America, I felt my life was good.

Then, illness struck. Like a thief in the night, it overtook me and within a matter of a few months, my life had changed forever. Gone was my job, gone were most of my friends, gone was our contented home life, and gone were my dreams of a happy and peaceful future. Once illness walked in the door, I had to learn to rebuild my life all over again, step by painful step.

After surviving a near-fatal illness in 1995-1996 of the colon and small intestine, I developed osteonecrosis, a.k.a. avascular necrosis, in several major joints. It turned out that the massive doses of steroids I was given for my illness were the culprits; I survived the illness, but my skeleton did not. Left alone in my house for four years, unable to walk or drive, I turned to my computer - my 'life-line to the world' and reached out to others with this strange disease. I created a simple webpage called "Marie's Breakfast Nook," and never in my wildest dreams did I ever expect to hear from anyone! Almost immediately, I heard from a woman from Long Island, NY. She, too, had AVN and was very eager to talk with me. That was just the beginning. Within six months, we had grown from a group of two to nearly 70. My simple webpage mushroomed into a nearly 20-page site, which was called "The ON/AVN Support Group International."

Within a year, our group had swelled to nearly 500 people who hailed from all over the world. We were hearing from men, women, teenagers, and even parents of younger victims, and all of them virtually were saying the same thing: "I thought I was all alone in this!" In the first two years of our group, we had amassed an army of nearly 3,000 people, all of them suffering from AVN. The thing that always tickled me the most is that all of this was accomplished without my ever having to leave my house!

Then, one wonderful day, I received an email from a doctor in Pennsylvania, asking me to con-

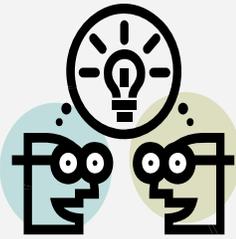
tact Dr. David Hungerford of Johns Hopkins University, a doctor who somehow had heard about our group and wanted to meet me.

On a balmy day in July 1999, Dr. David Hungerford, Dr Lynne Jones and Barbara Kelly flew up from Baltimore to my home in New York, and we had a wonderful meeting. On that historic day, I finally realized that there was hope again, that someone who really knew about AVN and understood it, also cared very deeply for its victims. Dr Hungerford told me that he was amazed at my group and what I had managed to accomplish. He also told me that he and a few other doctors had begun a group called the National Osteonecrosis Foundation, and that they needed to reach patients and doctors alike. I agreed to help. The ON/AVN Support Group International and the NONF websites exchanged links and I was asked to become the Executive Director of NONF. I was the Executive Director for five years, but had to step down this past January when our own group became an official non-profit organization. It is an honor that I cherished, and held very dear. It gave me the official stamp of approval to keep on gathering people, to keep on helping to educate and encourage them, and to give them hope.

More than anything in the world, we AVN'ers, as I call us, need hope. This cruel affliction takes away much more than just our joints and bones: it takes away inner peace and joy as it depletes our physical abilities and strength. It takes away the freedom of independence, and in so many cases, it often destroys relationships as well. It is tough enough for a couple to deal with family finances today without having to face expensive tests, operations, rehabilitation therapy, and medications. Often the strain of an illness such as ours is just too much for a relationship to bear, tearing it apart at the seams.

Today, our once-online only 'ON/AVN Support Group International' has evolved into the ON/AVN Support Group Int'l Association, Inc. as an official non-profit organization with a membership spanning the globe. We can be reached via the internet at <http://osteonecrosisavnsupport.org> or by regular U.S. mail at Box 118, 8500 Henry Avenue, Philadelphia, PA 19128. All those who are looking for support, comfort, and knowledge about AVN are welcome to join us.

Written by Marie Shanahan



**Help us help
you!**

*Please fill out the
survey at the
end of this
newsletter.
We want to
make NONF
better!*



Meet Nicole Willis (Volunteer)

Nicole Willis, the Associate Director of NONF, is also an ON survivor. As a result of high dose steroids she took to treat leukemia in 2001, Nicole quickly developed osteonecrosis. Between 2002 and 2004, she had both hips, a knee and a shoulder replaced, and still suffers from ON in several other joints. While going through treatment, Nicole was easily able to find information about and support for her leukemia, which helped her immensely to cope with the disease. However, when she searched for information and support for her osteonecrosis, she found very little. She needed help, but it wasn't there. After discovering NONF, she used this as her incentive to help NONF better focus on patient issues.

Nicole, who has a master's degree in public health, currently works as an epidemiologist in clinical research. Her clinical experience includes research in oncology, vaccines and

chronic diseases. She has experience in program planning and evaluation, survey development, database management, data analysis and many other areas that will benefit NONF.

In her personal life, Nicole enjoys volunteering for both the Leukemia and Lymphoma Society (LLS) and the Liberty Golden Retriever Rescue. As an LLS volunteer, she serves as a patient ambassador speaking at fundraising events. She also serves as an LLS first connection volunteer, telephoning newly diagnosed leukemia patients to talk with them, answer their questions, and offer them comfort and hope. As a Golden Retriever Rescue volunteer, she fosters dogs until they find a new home, she conducts home visits to ensure safe, pet-friendly environments for the adopted dogs, and has developed the group's new volunteer information brochure. Nicole will be a great asset to facilitate NONF's future growth and success.

"Osteonecrosis patients need a place to go for information, support and understanding. NONF will be that place."

Volunteers Needed

Volunteerism is an excellent example of a "Win-Win". On the one hand, it provides an opportunity for the volunteer to help others in need – especially for the relatively "unknown" disease of osteonecrosis. On the other hand, it helps a foundation during its early stages of growth to find people to help the foundation to get things done.

The NONF is searching for an Executive Director to oversee the daily operation of the Foundation. But it doesn't stop there. We also need individuals to help with secretarial functions, patient membership recruitment, membership services (new applications, renewals, database), grant writing and/or fundraising, web management, newsletter – content management, marketing/publicity; accounting; and local outreach (Speakers Bureau & Local Patient Meetings). The home office is currently in Baltimore. But with the internet, volunteers can live almost anywhere. If you are interested in finding out more, please contact us at 410-532-5985 or ljones3@jhmi.edu.

We would like to thank Debi Ross for all the hard work she has done on the NONF website!

Please complete the survey on the following pages and

email to: nicole.willis@gmail.com

or

mail to: Nicole Willis
3917 Cresson Street
Philadelphia, PA 19127

NONF Needs

This survey is designed to help us further develop NONF and address the issues that are important to you.

Medical Research

1. How important is it to you that NONF to provide information about current medical research for ON?

- ₀ not at all important ₁ somewhat important ₂ very important

2. How important is it to you that NONF to provide information about clinical trials that you could join?

- ₀ not at all important ₁ somewhat important ₂ very important

3. Do you understand the medical information about ON that is presented on this website?

- ₀ No ₁ Yes

If no, please specify what you do not understand _____

4. What specific medical aspects of ON would you like more information?

ON Treating Physician Information

5. How important is it to you that NONF to develop a nationwide list of physicians specializing in ON?

- ₀ not at all important ₁ somewhat important ₂ very important

6. How important is it to you that NONF to provide these physicians' contact information?

- ₀ not at all important ₁ somewhat important ₂ very important

7. How important is it to you that NONF to provide a list of these physicians' publications/research activities?

- ₀ not at all important ₁ somewhat important ₂ very important

8. What other information about physicians who treat ON would you like to know?

Patient Services (check all that apply)

9. Would you be interested in professional advice on the following topics?

- ₁ Nutrition
- ₂ Exercise
- ₃ How to talk to your doctor
- ₄ How to talk to your employer
- ₅ Physical therapy
- ₆ Assistive devices (canes, crutches, wheelchairs, etc.)
- ₇ Care/family support
- ₈ Pain management
- ₉ Treatment options and outcome data

10. What would you like to see on the NONF website? (check all that apply)

- ₁ Be able to tell your story and read other patient stories

- ₂ Osteonecrosis jokes and fun
- ₃ National Osteonecrosis Foundation store
- ₄ Provide links to egroups that provide communication with other patients (i.e. chatroom, blog)
- ₅ Look for advice and/or offer advice to other ON patients
- ₆ Learn about obtaining disability benefits
- ₇ Find financial aid
- ₈ Ask a doctor a question about your ON
- ₉ Volunteering for NONF
- ₁₀ Osteonecrosis advocacy: Please specify _____
- ₁₁ Osteonecrosis events
- ₁₂ Donating money to NONF
- ₁₃ Quarterly Newsletter
- ₁₄ Other _____

About You

11. Age: ₀ under 20 ₁ 21-30 ₂ 31-40 ₃ 41-50 ₄ 51-60 ₅ 61-70 ₆ 71 or older
12. Sex: ₁ Male ₂ Female
13. Total number of joints affected: _____
14. Joints affected: ₀ hip(s) ₁ knee(s) ₂ shoulder(s) ₃ ankle(s) ₄ elbow(s) ₅ jaw ₆ other _____
15. Working status:
₀ full time ₁ part time ₂ unemployed by choice ₃ unemployed (looking) ₄ unable to work
16. How did you hear about NONF?
₀ web search ₁ doctor ₂ family/friend ₃ support group ₄ other _____
17. Is there any other information or services not mentioned that you would like to see NONF provide?

NONF Membership

18. When you joined NONF what did you expect your membership to provide? _____
19. What do you believe the most important function of NONF is? _____
20. What has NONF done the best in meeting your expectations?

21. What do you think NONF needs to improve? _____
22. After you receive treatment for your ON, how likely are you to maintain interest in ON-related issues?
₀ not likely ₁ somewhat likely ₂ very likely
23. What, if any, are the issues important to you that have not been mentioned in this survey? _____

Thank you for participating in this survey. We will try our best to meet your ON needs. Please send an email to nicole.willis@gmail.com with any suggestions to develop NONF or the NONF website that have not been mentioned in this survey. Thanks again.