Prepared Remarks of Jim Hindman for Fenwick Island Lions Club September 21, 2015

Jim Hindman on Macular Degeneration and the Low Vision Rehabilitation Network (LOVRNET) for the Fenwick Island Lions Club

For all of us at the Hindman Foundation, I want to say "thank you" for having us to your club this evening to talk with you.

Lions Clubs are an amazing organization and a necessary and exemplary piece of the American spirit of volunteerism. As I familiarized myself with the Fenwick Lions, I have to say that I was blown away by all the work you do. Meals on Wheels (along with countless other food-drives and food services); providing scholarships; recycling; and, of course, a commitment to vision.
It is, in fact, the cause of vision which bring us here to speak with you tonight.

I hope you realize that you Fenwick Lions are blessed, uniquely positioned with access to the world's leaders in eye care. With the Delaware Eye Institute a stone's throw from where we are tonight; and the Wilmer Eye Institute in Baltimore, and Wills Eye Hospital, the Scheie Eye Institute, and Salus Univeristy (the world leader in optometry training) all close by in Philadelphia, you have access to the top professionals and the leading research in the field of vision care.

Unfortunately, many people do not have that same access.

Here's a number for you ... did you know that there are over 11 million Americans who have age-related macular degeneration, today? Eleven million, and you're looking at one of them right now. Look around the room and you will see many more, because 1 out of every 3 people over the age of 75 will be diagnosed with AMD. If that is not enough, the number of people with AMD will increase to over 25 million in the next 25-30 years. The odds are that most of us know someone with AMD, if we do not have it ourselves. It is, in fact, the leading cause of blindness in America. Yet, how much do you and I hear about it, and how much do we know about? Not much on both fronts.

Briefly, for those of you who aren't that familiar with AMD, let me explain that age- related macular degeneration (AMD) is a degenerative eye disease which impacts the macula of the eye, the part of the retina responsible for clear, central vision and focus. When you first get AMD you likely won't even notice it. It doesn't feel like anything and your eyes will compensate for any initial vision lossso that you won't really be aware of it. Eventually, however, over the course of months or maybe even years, you will notice some blurring and distortion. Ultimately, black spots grow in your vision so that whatever you are looking directly at is obscured right in the middle. If you make two fists and hold them right up to your eyes that is pretty much what it looks like to have AMD. You can see peripherally, but nothing in the middle.

As I just hinted at, when I was diagnosed with AMD 23 years ago, at the age of 57,1 had no symptoms whatsoever. I went to Johns Hopkins with my mother-in-law because she was experiencing vision problems and was afraid to go alone. I volunteered to have the same procedures she was having, and lo-and-behold, we both had AMD! At the time I really had no idea what AMD was, so the diagnosis didn't really impact me. They might have explained the disease, but since I wasn't experiencing any vision problems I just kind of listened and moved on.

For 12 years my vision remained relatively stable. Along the way I started taking AREDS vitamins, which have been proven to delay the advance of AMD once you are diagnosed with it. More or less, though, I didn't do anything to help my cause. My vision was okay, I felt fine, so I just went about my life.

In 2004, 12 years after my diagnosis, my vision took a turn for the worse. I returned to the Wilmer Eye Institute at Johns Hopkins and upon examination they could see that the AMDhad progressed. There is little I remember about 2004,1 barely remember what 1 had for dinner last night, but I do remember the doctors telling me, "You're going blind and there's nothing you can do about it." Talk about a diagnosis! "You're going blind ... good luck." Wow! What a devastating feeling.

I bet you know someone, or maybe you are the person, who has heard that same diagnosis. Well, I am here to tell you that it isn't true. But, I'll get to that later!

So, it is 2004 and I am told I'm going blind and there's nothing I can do about. In a matter of 10 months the vision in my right eye decreased from 20/40 to 20/400. In 2010 I became legally blind, with vision of 20/400 in both eyes.

Over the course of those six years, from 2004 when I got the news that I was going blind, and 2010 when I became legally blind, I experienced steady vision loss. It was a frightening and depressing time. When you lose your vision you lose your independence, freedom, confidence, purpose ... in short you lose hope. What reason did I have for hope anyway? My doctors told me there was no hope. Blindness was my destiny, now it was up to me to deal with it.

I can tell you all the things I gave up and lost as I lost my vision—reading, friends, going to social events, driving, businesses, watching my grandchildren play their sports—but it really is impossible to describe what it is like to have some disease rob you of your vision and so rob you of the things you love most in life. I can tell you that I experienced depression. I can tell you that for the first time in my life I just about gave up. I was close, but I didn't. So, when I say, Never, Never, Never, give up, I mean it and I lived it.

In 2012 a friend, the father of a former football player of mine at Western Maryland College, called me and told me about an article he had read about some exciting new procedure taking place at USC which was supposedly restoring vision to AMD sufferers. The article was about an implantable miniature telescope which was surgically implanted into the eye and which projected a larger image onto the macula, thus making it possible to see more clearly again. I knew I was going to get that device. For the first time, I had a feeling of hope.

I was ready to head to California when I was told that the surgery could be done at Johns Hopkins. I should note first—however great the care there is, they didn't contact me about the IMT. I wrote to them telling them of my plans to go to California. Apparently, to them, I was just the guy who was blind and had to deal with it. This is not to knock the great professionals at Johns Hopkins, or anywhere else, but the fact is if you don't advocate for yourself no one else is going to either.

In December 2012 I got the IMT surgery at Johns Hopkins and, after a long rehabilitation process, my vision improved from 20/400 to 20/60 in the IMT eye. With the restoration of my vision came the restoration of my hope and purpose. The rehabilitation process, like my entire experience with AMD, was essentially disorganized and uninformed. While I was the first patient at Wilmer to get the IMT, I was not the first patient to get AMD. In other words, there was information out there that I knew could help me, but for some reason I wasn't being told about it.

There are so many exciting things going on in the field of AMD and low vision that people need to know about but don't. There are over 1,200 research projects having to do with AMD listed right now on clinicaltrials.gov. We have been in contact with a woman from England who recently had a different kind of miniature telescope implanted in her eye, a telescope based on the Hubble design. She has telescopes in both eyes and her goal is to drive again. Ain't it great! There is stem cell research going on. We saw a video while visiting the Scheie Eye Institute about a young boy who had been blind his entire life, but after receiving an experimental surgery was outside playing catch with his father. This is the kind of information that gives people with vision loss hope.

So, we have set out to raise awareness about AMD and all the things that we, as sufferers, family members, or volunteers, need to know about to help ourselves and help others. That is the goal of the Hindman Foundation, to raise awareness about AMD and to let people know that there is help and hope out there for them.

Help and hope are two things the Lions have been giving to people with visual impairments since 1925, when Helen Keller challenged the Lions to become the Knights of the Blind. This is a challenge the Lions have accepted with vigor.

Over the nearly 100 years since receiving that charge the Lions have served nearly a half billion (with a B) people worldwide. In the last 25 years alone, the Lions have raised more than $500 million for vision causes. The Lions have saved the sight of more than 15 million children worldwide by providing eye screenings, glasses and other treatments through Sight for Kids. The Lions have helped another 120 million children through the establishment or improvement of pediatric eye care centers. The Lions have funded the training of more than 650,000 eye care professionals and have built 315 eye hospitals, improving the vision of another 100 million people around the world. The Lions have distributed over 147 million treatments for river blindness. The Lions have provided nearly 8 million cataract surgeries. The Lions have vaccinated 41 million children in Africa against measles, the leading cause of childhood blindness. The Lions have, the Lions have, the Lions have ... In short, the Lions have changed the world because of their commitment to being Knights of the Blind. And, the Lions continue to change the world through this commitment.

Today, the most exciting project, I think, of the Lions, is a project called LOVRNET, being piloted right here in our backyard, throughout MD-22. Let me take a minute as I close to talk about LOVRNET and how important your involvement in this program is.

LOVRNET stands for Low Vision Rehabilitation Network. It is a Lions program, funded by LCIF and the Reader's Digest Partners for Sight, and is property of LVRF, which I know the Fenwick Lions are a sponsor of. To explain LOVRNET most simply, the program will serve to connect low vision patients with the resources and rehabilitation services they need. The program is built upon the volunteer service of the Lions, who will act in one of four capacities: 1) being advocates for LOVRNET at the local club and community level; 2) conducting phone interviews to help get patients into the system; 3) scheduling patient appointments, to make sure patients are being helped by the system; 4) and, providing direct care to patients, by driving them to their appointments or helping them around the house, thus making the system work. So, there is something for everyone and I would urge you to get involved.

While today LOVRNET is an MD-22 project, the plan is to roll it out nationally, to all 48 multiple districts, and eventually internationally. LOVRNET is essentially a community based healthcare initiative that will change the way patients get connected to the services they need. It is a revolutionary product and we are excited to be a part of it and to know that clubs like the Fenwick Lions sponsor programs like this through giving to LVRF.

Why is a program like LOVRNET so important? Because, as I have hopefully explained, the current low vision care paradigm is not serving the needs of the patients. "You're going blind and there's nothing you can do about it" is not advice doctors should be giving their patients. And, it isn't true. So, why do people continue to hear this from their eye care professionals?

Think about this analogy. You fall and hurt your hip and go to an orthopedist. He tells you you have a broken hip. That is his job, he diagnoses you. What if that is all that happened? You hurt your hip, you're told your hip is actually broken, and the doctor says, "You have a broken hip and there's nothing you can do about it." But that's not what happens. Why? Because you get a prescription for physical therapy! That's it. That is the difference. Where, in other medical fields, the process goes from diagnosis to referal, in vision the process goes from diagnosis to "good luck." It is a simple step, a necessary step, but it isn't getting done today. LOVRNET is going to change that. But changing the paradigm is going to take people like you to care about the problem and get involved to help solve it.

As a Foundation we have found another exciting opportunity to help change the paradigm of care. Partnering with the Reader's Digest Partners for Sight Foundation, which again is a lead sponsor of LOVRNET, we are helping to fund the production of a video for the American Academy of Ophthalmology about the importance of referring patients to low vision rehabilitation. We are excited because the training video will be completed in 2016 and will be shown to over 300,000 eye care professionals. It is a small but necessary piece in changing the paradigm of service for low vision patients. You can get help by giving to our Foundation, and every dollar that we give to the cause is going to be matched by the Reader's Digest Partners for Sight Foundation, so it is a great return on investment!

In closing, I want to again applaud you for your efforts as Lions, as Knights of the Blind. What you do really does matter. It really does change lives. I also want to encourage you again to get involved with LOVRNET. Learn about it and then volunteer. You can contact them directly at 410-737-2671 or at lionsvision.org.

I also want to ask for your support for our Foundation, by either buying a book, which is full of valuable information about AMD and living with low vision, or giving directly. Again, we are proud to be working with the Reader's Digest Partners for Sight in funding the production of this important video and any money you can give to us will be doubled by a match from Reader's Digest. * See below.

So, get informed. Get involved. And keep serving. Thank you.

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**Currently, the Hindman Foundation is supporting a film project, which will be supervised by the Vision Rehabilitation Committee of the AAO under the direction of Joseph Fontenot, M.D., that will encourage eye doctors and other health personnel to address the functional, emotional and social needs of those impacted by vision loss. This will be done by stressing the impact of vision loss and suggesting efficient systems for education and referral. The 6 minute long video will be distributed by the American Academy of Ophthalmology, the American Society of Retina Specialists, Optometry Associations, ophthalmic technician societies and others. They have raised $60,000 so far, and need to raise another $10,000 to reach their goal.*

Donations up to $5,000 will be matched by Reader's Digest Partners for Sight Foundation. The foundation has been granted 501(c)3 status by the Internal Revenue Service, so donations are deductible, to the full extent of the law.

The foundation can be found on the web at: http://hindmanfoundation.org/ and click on "Donate" toward the bottom of the page. Or, send a check, made payable to the Hindman Foundation, to:
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