$\frac{2}{ANNUAL}$ REPORT

RESEARCH | EDUCATION | SUPPORT

MOVING FORWARD REIMAGINE A FUTURE



Grea Pruitt

CONGRATULATIONS
AND THANK YOU

to the entire SPFoundation community for all of the efforts you were part of which brought so many new members to the SPFoundation family, multiplied the work of the foun-

dation and, most importantly, raised more funding resources than ever before (\$1,138, 263) in 2021! The increase in resources mean that we can fund more research to find treatments and cures that everyone in the SPFoundation family desperately need. Frank Davis, SPFoundation President for the past ten years, has set an outstanding example for all of us in his unwavering commitment to giving to SP-Foundation. His excellent leadership and constant focus have been very important elements in this success. On behalf of everyone affected by HSPandPLS, I want to thank him for everything he has done in this work and will continue to do. Frank is not stepping down, only stepping back as we appreciate his willingness to continue serving the board of directors as our President Emeritus. We genuinely need his experience and insight to keep SPFoundation moving forward as we reimagine future possibilities for the SPFoundation.

The challenges we had to face in 2020 remained with us 2021, but you and the SPFoundation continued to advance. Another virtual conference brought many members and researchers together from across the world. All four of the SPFoundation committees, Marketing, Fundraising, Research, Education and Ambassadors, as well as your board of directors, continued to meet monthly by Zoom to keep the foundation's work moving forward. The work of the committees is a very important

component in the foundation's work. Each of the committee chairs has provided a short summary/report of their 2021 work. Please encourage in any way possible these committees in their focus areas. Feel free to contact the committee chairs if your talents and skills can assist or support in our moving forward.

The research and development that SPFoundation is currently funding is listed in this report by researcher and project title. More detailed information regarding those projects can be reviewed online at SP-Foundation.org. The Research Grant Committee and Scientific Advisory Board are currently working diligently to determine the next research projects to recommend for funding to the board of directors. We are going to be able to fund more research over the next six to nine months than in any similar previous timeframe. Again, thanks to everyone who contributed to this possibility. Every contribution received in 2021 makes this possible. We have many generous and big-hearted donors helping to find a cure. Whether it be a one-time donation, a recurring monthly donation, or part of the magnificent year-end Match My Gift program, every gift brings us closer to treatments and cures which will improve the lives of those of us who have either of these diseases and will make the future brighter for those who may have them in the future. The SPFoundation Board of Directors continues to maximize your donations, as 97% of each dollar raised supports the foundation's mission of research, information and support. Much of that 3% is utilized to produce and mail our Synapse newsletter and the Annual Report, as well as host the website and donor management platform. We are very fortunate to continue to have management and administration functions such as legal, accounting, income tax preparation, medical grant review, website

oversight and maintenance, and daily foundation management services provided at no direct cost. We continue to move forward utilizing more online communication to be efficient and expeditious with resources and information. We want to thank all of those who donate their personal and professional time to provide these necessary services. The financial contributions from every donor and the value of volunteered professional services make it possible to apply every possible donated dollar to the needed and necessary medical research.

A common goal of all the committees is to nurture and expand awareness and funds for HSPandPLS. Increasing awareness will multiply the number of people that will help and engage people to reach our new fundraising goal. Upon the recommendation from the Fundraising Committee, your SPFoundation Board of Directors has launched a fundraising goal of \$1.5 million for 2022. Not everyone will

become a major donor or even a recurring donor, but you can instead encourage people to spread the word about SPFoundation seeking to find a cure. Be a good volunteer, give of your time, to help raise awareness and funds. We thank all of you for your past support, and respectfully ask you to aggressively join us in reaching this 2022 goal. We believe that staying positive and aggressive in our work and research, and in partnership with others all over the world researching these diseases, we will soon find answers that will make major differences in the lives of every individual and family affected by HSP or PLS. It is essential that we make this happen as we move forward and reimagine a future without HSPandPLS.

Best Always,

Irea Pruitt

SPF President



Frank Davis

Dear Friend,

It is exciting for me to be passing the Spastic Paraplegia Foundation presidency on to such a remarkably capable and talented man as Greg Pruitt and, of course, his wife Norma. All of you that attended our recent Annual Conference in Nashville know what a

capable and flawless job Greg and Norma did in putting that together. Believe me, that took a lot of work!

As with any organization whose mission is to cure diseases, understanding some of the terminology and science can sometimes be challenging. I have been working with this foundation for 18 years and I still need to keep a dictionary handy when I read these reports.

Despite the challenge, please know that these are incredibly exciting times. There is tremendous promise and hope for people suffering with HSP and PLS. Never has there been a time when so many very exciting possibilities lie before us. We have to keep stepping forward to the challenge. These new promises have to be pursued. That means each of us needs

to keep being generous with our donations to The Spastic Paraplegia Foundation so we can make it to our fundraising goal of \$1,500,000 this year.

The Spastic Paraplegia Foundation has been laying the foundation since our inception in 2002 for most to all of the current HSP and PLS studies all over the world. Most of you have heard about the Clinical Trial for SPG50 and there are several other studies coming close to fruition for several different types of HSP. Additionally, there is an Upper Motor Neurology drug, developed by Dr. P. Hande Ozdinler that is very close to coming to clinical trial for people with HSP, PLS and ALS.

It is with bittersweet feelings that I realize this is the last annual report of the Spastic Paraplegia Foundation that I will play a part in. I will continue to be on the SPF Board of Directors but plan to spend more time trying to travel, see the world and spoil grandchildren in an appealing, relaxed way. I have enjoyed working with so many of you over the years and hope we can continue to work together in the future as the need or occasion arises.

Frank Davis

SPF President Emeritus

SPF COMMITTEES — WORK OF THE SPFOUNDATION

AMBASSADORS AND EDUCATION COMMITTEE

The primary focus of the SPFoundation Education and Ambassador Committee (E&A) is to spread awareness of HSP & PLS and educate every one of our rare diseases, specifically Patients, Family, Caregivers, Physicians/PT, and the General Public. The E&A Committee meets via Zoom on the third Wednesday of the month at 7:00pm CST. An agenda is sent prior to the meeting so others may prepare their input for additional discussions. Afterwards, the meeting minutes are sent to the E&A members so they can follow up on discussions, helping with the importance of educating and supporting our community.

In addition to education, the committee is a place for Ambassadors to share ideas on how to contact members of our community and discuss ways to get more people involved. The Ambassador role is evolving as more people are interested in being added as an ambassador. With input from our population, an informational pamphlet for "Your Role as an Ambassador", as well as additional resources can be found online at SP-Foundation.org.

A great deal has been accomplished, created, and discussed, since the Education Committee was formed in 2018. Many accomplishments include the following highlights:

- Obtaining corporate sponsors for the annual conference
- Soliciting donations of medical equipment for the annual conference to raffles and door prizes
- Updating SP-Foundation.org and adding testimonials from our population
- Updating SPF members information on Network for Good (NFG) platform
- Updating a listing of the recommended doctors familiar with HSP or PLS on SPFoundation.org
- Updated welcome letter for new members to SPFoundation
- Added a letter that outlines the SPF website
- Created a SPFoundation Informational "business" card

- Recommended to the SPFoundation Board signing a petition from World Health Organization (WHO) to proclaim October 17 as World Hereditary Spastic Paraplegia Day
- Wrote an introductory letter and sent to Movement Disorder Clinics, medical schools, and clinics to spread awareness of HSP, PLS, and SPFoundation
- Compiled an introductory letter to ALS Clinics and sent to them to spread awareness of HSP and PLS
- Developed a list of addresses for ambassadors to help connect and provide outreach efforts within the ambassador family of SP-Foundation

Discussion items:

- SPF Annual Conference
- SPF Webinar Series Monthly presented by doctors
- SPF Talks Subject-Matter Experts and Patient discussions
- SPF Awareness Week
- SPF 5K Run Walk Roll Fundraiser and Events
- SPF Synapse and Spastic World
- SPF YouTube Channel
- SPF End of Year Giving Campaign
- SPF Hot Pepper and Hot Wing Challenge
- Giving Tuesday
- Abilities Expo
- SPF Patient Insight Network
- Amazon Smile

Future items:

- Welcome Postcard
- Welcome Videos
- Spoon Theory Postcard
- Discussions regarding possible travel grants for SPF members for the SPF Annual Conference
- Members donate/pay for printed Synapse
- Auto-generated Welcome Email when someone joins SPF
- Form to become an ambassador
- Ambassador training

If you would like to serve on the SPFoundation Education and Ambassador Committee or would like to provide ideas or feedback, please contact Dina Landphair at Dina.Landphair@sp-foundation.org

FUNDRAISING COMMITTEE

THANK YOU to every member, partner, contributor, and donor for your effort and participation with SPFoundation in 2021. On behalf of the SPFoundation Fundraising Committee, we simply want to say, "We Appreciate You!" Last year, over \$1 million was raised through all our efforts. This is the most ever raised!

The 2021 financial information in this report clearly indicates an increase in resources for the SPFoundation. Your direct efforts and contributions are assisting the SPFoundation in raising more resources than ever before. Resources that increase important research to move us closer to the treatments and cures that are so very important to those of us who must daily handle and endure HSP or PLS.

Fundraising Committee work is accelerating with the assistance of more new members and contributors. With growing awareness, the committee enthusiastically recommended a 2022 fundraising goal of \$1.5 million to the SPF Board of Directors early in the year. Without hesitation and with great commitment, the Board unanimously adopted the expanding goal and is working with the Fundraising Committee to ensure that medical research continues moving forward at an accelerated pace.

The Fundraising Committee offers the following examples to expand your fundraising base to help you contribute financially to the SPFoundation:

Online giving through SPFoundation. org is the quickest, easiest, and most cost-efficient for the Foundation. Make a single contribution or set up a recurring plan. Monthly or quarterly contributions can easily be setup and amended at any time with autopay on sp-foundation.org. As soon as your online contribution is processed you will receive a quick response thanking you for the donation and providing an automatic tax receipt for your records.

Personal checks are always a mail-in option. It takes valuable time and resources to process checks to ensure the donation is properly coded in the

system and the donor is properly acknowledged with a Thank You letter. To help assist our volunteers to be more efficient, SPFoundation prefers online donations if possible.

Honorarium and Memorial Contributions is a heart-felt way of acknowledging your loved one with a webpage specially created for them online through SPFoundation's "Memorial Giving Honoring Love Ones in SPF Circle of Love". Please let us know if we should notify someone about your honorarium and memorial contribution. https://sp-foundation.networkforgood.com/projects/140175-memorial-giving-honoring-love-ones-in-spfcircle-of-love

Facebook Fundraisers are another great option for raising money for SPFoundation. Creating personal fundraisers can bring people together, yet be far-reaching in benefit for a great cause like the SP-Foundation. Facebook makes it easy to create and share so family and friends can easily donate securely through Facebook.

AmazonSmile is an easy way to generate money without directly contributing yourself. AmazonSmile donates 0.5% of your eligible purchases to SPFoundation, at no extra cost to you when you select SPFoundation as your charity on AmazonSmile. Log in to your Amazon account, select Account and Lists in the top dropdown menu, select "AmazonSmile Charity Lists" to select SPF as your non-profit. Ask family and friends to do the same. This possibility can raise significant resources without costing the on-line purchaser.

Employer-Matching Programs may be available through your employment. Contact your human resource or personnel department to see if your employer has a program to match your charitable contributions. It is usually easy to sign up. Let them know when and how much you contribute to SPF, and your gift may be matched by your employer.

Planned Giving is another great way to contribute to SPF for medical research. It may be accomplished in several different ways. Some are including the SPF in their last will and testament. Making the SPF ben-

eficiary of trusts or life insurance policies are other possibilities. Please check with your financial advisor and/or attorney to consider these types of contributions. In 2020 after we lost a hard-working member of our population, Mr. John Staehle. The SPFoundation created "The Staehle Legacy League' in his honor so members can name SPFoundation in their will, trust, retirement plan, life insurance policy or annuity. For more information about planned giving or if you would like to notify SPFoundation that you are participating, please contact us Information@SP-Foundation.org or call (877) 773-4483.

Donate Appreciated Securities, funds from 401K, or other financial investments. Check with your financial advisor regarding the proper process and timing should you desire to consider this type of contribution. Contact SPFoundation for wiring instructions.

Many businesses have foundations set up to help them save money while helping the community. If you have a connection with a business, please check and see if they make contributions to non-profits. If so, they might contribute to SPFoundation in your honor. Contact SPFoundation for assistance with the application process.

Corporate Sponsorships is another effective way to help raise money for SPFoundation. Through the SPFoundation Sponsorship Program we can partner to provide marketing opportunities for businesses and nonprofit organizations through SPFoundation online resources. Contact SPFoundation for assistance with the Sponsorship Program.

There are several events, campaigns, and fundraising opportunities that happen year around. Details are communicated via email, social media, and e-blasts. Please keep your email updated with SPFoundation so you can be informed of upcoming activities. SPFoundation is your foundation for your rare disease. We need everyone, along with family and friends to help to reach the fundraising goal this year and raise awareness to reach more people with HSP or PLS.

Please help us reach our 2022 goal of raising \$1.5 million dollars by making personal

contributions, reaching out to family, friends, and asking business associates. Questions or comments about the Fundraising Committee contact, jim.sheorn@sp-foundation.org.

Jim Sheorn

SPF Fundraising Committee Chair

MARKETING COMMITTEE

The SPFoundation's Marketing Committee began in 2018 at the Annual Conference in Pittsburg. The SPF Board of Directors combined all communication and marketing efforts into one committee to advance its goals of research, education and support. The emphasis has been to increase the presence and awareness of the SPFoundation to physicians, neurologists, researchers, and to individuals with HSP and PLS. Members of the SPFoundation and community have listed as their number one issue, their being misdiagnosed for many years as they are enduring symptoms and effects of HSP or PLS.

The challenge before the Marketing Committee is to develop a creative message that could communicate to physicians, the medical community, and others to inform them of the SPF mission. The Marketing Committee is communicating who we are, what symptoms we have, and directing them to our website. To this point, it is also essential to carry the message to researchers and investigators that the SPFoundation has a scientific grant award program available to assist them in their efforts to study HSP and PLS.

In 2019, the Marketing Committee created a Spectrum campaign that afforded us the ability to target our message specifically to neurologists attending the American Academy of Neurology (AAN) Conference in Philadelphia, PA. Spectrum set-up a geo-fence, or a virtual fence, around the physical location of the conference site that sent our message/advertising directly to those in attendance via their laptops and mobile devices. Our messages included a combination of "Question and Answer" graphics designed to engage the viewer to click-through to the SPFoundation website for more details and

videos explaining our conditions. Spectrum reported that our advertising plan exceeded expectations by exceeding the national average of user engagement and click-thru rates bringing viewers to our website. During the AAN conference, our website analytics almost doubled from the previous month. With this success, we targeted the American Neurology Associations (ANA) conference in St. Louis, MO., later in 2019, aiming our message to researchers. As before, our ads exceeded expectations, with increased website visits and it contributed to an increase in the number of grant Request for Proposals (RFP) from researchers.

As 2020 rolled in and out, we expanded our capacity focusing to reach our audience without the ability to meet in-person. The Zoom video conferencing service allowed us to virtually create our first Virtual Annual Conference with an aggressive list of speakers, physicians, and medical researchers, all of which can be viewed on SPFoundation You-Tube channel. The Zoom service also helped to bring us together for HSP and PLS Awareness Week.

The process of reorganizing the SPF website, cleaning up duplicated and outdated information, etc., was a huge task, but now we are immensely proud of the volunteers that took on the challenge to make the website even more user friendly. The Marketing Committee created a new video message for the Combined Federal Campaign, a workplace giving campaign platform for federal employees and retirees. We encouraged members to participate in our HSP and PLS Awareness Week in late August and our social media platforms began exploding with our members' activities and fundraising events.

Continuing with our successes into 2021, the Marketing Committee expanded SPFoundation's global presence. Our series of seven webinars over four months was heavily attended, bringing members from around the world together to hear from our researcher and doctors. Participates attended our Zoom webinars from 26-counties.

With a renewed energy and presence, our membership is growing, participation is increasing, fundraising goals are exceeding initial expectations, and more people are marketing and fundraising personal campaigns the year. The addition of the SPF Store allows a creative flair for a message of enduring life with HSP or PLS, promoting SPFoundation, and making new items available to raise awareness while providing residual revenue to the SPFoundation.

Fast-forward for a 2022 update, as technology continues to advance, the Marketing Committee worked through Spectrum to develop the ability to not only focus our message to the AAN Conference in Seattle, WA., in April, but also to send the attendees our ads for an additional 30 days after they returned home. Plus, we were able to target the Top 10 research universities in the United States with our ads. SPFoundation now has more than 500 researchers in our database to receive our message that grants are available through SPFoundation to research HSP and PLS, and we are currently evaluating over 30 proposals. During 2022, we also hosted an in-person annual conference in Nashville, TN.

It is quite humbling to be a part of a community that so passionately tells its stories of enduring life with HSP and PLS, along with those with complicated and unknown variants. Our families, community and membership continue to grow and our message and vision will continue to focus on "the day when all individuals with HSP or PLS are diagnosed, treated, and cured."

Be a part of the Marketing Committee to help us support SPFoundation. Questions or comments about the Marketing Committee please reach out to us at Information@ SP-Foundation.org.

SPF Marketing Committee Chair

RESEARCH GRANT COMMITTEE

The mission of the SPFoundation Research Grant Committee is aimed at converting donations into grant awards for researchers, scientists, and investigators to produce scientific research and therapies for patients with HSP and PLS. The process consists of identifying researchers to send a request for proposal, identifying the best research proposals, then funding the proposed research. This process is completed through the volunteer efforts of the SPF Research Grant Committee (RGC) and SPF's Scientific Advisory Board (SAB).

To put it in perspective, the SPFoundation awarded two proposals for \$40,000 each in 2003. In 2021, SPFoundation has pledged grant awards of \$771,000 to research across six distinct proposals. Scientists have unraveled many of the riddles regarding the complicated biochemistry of these diseases. Many HSP genes have now been discovered, as well as a gene for PLS. More research is essential.

Fast-forward for a 2022 update. With the assistance of many donors, sponsors, and contributors, the SPFoundation set a record in fundraising, collecting \$1,300,000 that will be made available for scientific research. Further at the 2022 Annual Conference, Dr. Martha Nance, who is stepping down as Chair of the SAB, was honored with an award from SPFoundation, acknowledging our appreciation for her 19-years of commitment and service to SPFoundation. Also, Mark Weber was awarded for his service as SPFoundation RGC Chair. He is stepping back as committee Chair but will continue to remain active with the committee.

The SPFoundation has a remarkable team of people who are constantly accepting the challenge to utilize their experience and talents. John and Jody Cobb, the new RGC co-Chairs and Dr. Paolo Moretti, our new SAB Chair, are proceeding quickly to build on what Dr. Nance and Mark have accomplished over the past 20 years. Due to these shifts, the grant review cycle was delayed, but a plan has been formulated to get the 2022 grants funded before the end of the year.

Please help us reach our goals. Questions or comments about the Research Grant Committee contact, jodi@sp-foundation.org or john@sp-foundation.org

SPF Board Of Directors, Member Research Grant Committee Co-Chair

Jody Westbrook Cobb, PhD Research Grant Committee Co-Chair

RESEARCH AND DEVELOPMENTS

An increased focus on our diseases is timely and critical. There is indeed reason to hope for treatments and therapies in coming years that will restore significant function to people affected by HSP and PLS and other related diseases. Uncovering more of the riddles are leading to important findings for related conditions such as ALS, spinal cord injury and Alzheimer's Disease. Researchers say common threads link the many neurologic conditions that affect millions of people. Read more about the important research on SPFoundation.org.

Discovering New Hereditary Spastic Paraplegia Genes through Cutting-Edge Genetic Technologies

James R. Lupski, M.D., Ph.D.; Cullen Professor, Baylor College of Medicine, Molecular and Human Genetics, Houston, Texas

Dietary Supplements to Treat GPT2 Disease, a Metabolic Cause of Progressive Spastic Paraplegia

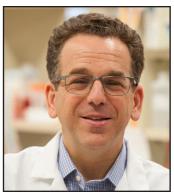
Eric M. Morrow, M.D., Ph.D.; Director, Center for Translational Neuroscience, Brown University, Providence, RI

Alteration in the Level of Cholesterol-derived Molecules Damages Nerve Cells in Hereditary Spastic Paraplegia

Nicoletta Plotegher, Ph.D.; Senior Postdoctoral Fellow, Department of Biology, University of Padova, Italy







Eric M. Morrow, M.D., Ph.D.



Nicoletta Plotegher, Ph.D.



Liang Qiang, M.D., Ph.D.

How Defective Autophagy May be the Cause for the Nerve Dieback in Hereditary Spastic Paraplegia

Liang Qiang, M.D., Ph.D.; Assistant Professor, Department of Neurobiology and Anatomy, Drexel University College of Medicine, Philadelphia, Pennsylvania

Understanding How Mutant Spastin Affects the Intracellular Movement of Organelles

Gerardo Morfini, Ph.D., University of Illinois

Identification of the Neuronal Transcriptomic Signature Associated With Lysosomal Defects in Hereditary Spastic Paraplegia SPG11

Typhaine Esteves, Liriopé Toupenet, Julien Branchu, Frédéric Darios, Daniel Stockholm and Giovanni Stevanin; Institut du Cerveau, Pitié-Salpêtrière Hospital, Paris, France

Using Mice to Understand the Cause of SPG4 Hereditary Spastic Paraplegia and Develop New Treatments

Peter Baas Ph.D.; Drexel University College of Medicine, Philadelphia, PA

Primary Lateral Sclerosis, Natural History Study

Hiroshi Mitsumoto M.D. DSc; College of Physicians and Surgeons Columbia University Neurological Institute

Discovery of Novel Mechanisms Underlying SPG3A Hereditary Spastic Paraplegia (HSP)

Dr. Holger Sondermann, Ph.D. & Dr. Carolyn Kelly, Ph.D. Candidate in Biochemistry; Department of Molecular Medicine, Cornell University



Gerardo A. Morfini, Ph.D.



Giovanni Stevanin, Ph.D.



Peter W. Baas, Ph.D.



DSc



Hiroshi Mitsumoto, M.D., Holger Sondermann, Ph.D.













Xue-Jun Li, Ph.D.

John K. Fink, M.D.

Alfredo Iacoangeli, Ph.D.

Peter Bede, M.D., Ph.D.

Sabrina Paganoni, M.D., Ph D

Using Patient-Specific Neurons to Explore the Treatment of HSP and PLS through Regulating Mitochondria

Xue-Jun Li, Ph.D.; University of Illinois, College of Medicine

Biomarker Analysis in Hereditary Spastic Paraplegia and Primary Lateral Sclerosis

John K. Fink, M.D.; Professor, Department of Neurology University of Michigan

Investigating The Genetic and Environmental Causes of Primary Lateral Sclerosis

Alfredo Iacoangeli, Ph.D.; Kings College London

Using MRI Techniques to Expedite Diagnosis in PLS and Monitor Disease Progression

Peter Bede, M.D., Ph.D.; Associate Professor, Consultant Neurologist, Head of the Computational neuroimaging Group, Trinity College Dublin Medical Patron, Irish Motor Neuron Disease Association (IMNDA) Fellow of the Biomedical Imaging Laboratory, Sorbonne University.

Imaging of Neuro-Inflammation in PLS and HSP

Sabrina Paganoni, M.D., Ph.D.; Massachusetts General Hospital

Activities Where your dollars go 97% 97% Mission 3% Management

Financial

REVENUE	2021	2020	2019
Donations	\$1,089,032	\$947,749	\$888,987
Team <i>W</i> alk	19,365	35,011	18,795
Special Events	0	N/A	29,500
Program Fees & Products	0	45,803	46,120
Investment Income	29,866	10,729	20,022
Total Support and Revenue	\$1,138,263	\$1,039,292	\$1,003,424
DIRECT EXPENSES			
Management and Administration	on 30,260	86,125	73,783
Program Expense	63,652	63,508	51,947
Mission	97%	92%	93%
Management and Administrat	ion 3%	8%	7%
Total Expenses	\$93,912	\$149,633	\$125,730
NET ASSETS (as of December 31)	\$1,115,751	\$851,834	\$1,002,209
GRANTS PLEDGED	\$771,000	\$888.904	\$800,000

and Administration

2021 DONORS

Platinum \$50.000-99.999+

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\$25,000-49,999

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Race Walker

\$500-999

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Janette Lounsberry

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Medical Advisor John K. Fink, MD University of Michigan, Ann Arbor, MI



Legal Counsel Mark Weber, Esq.

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