

# Meet our 2020 Inspiration Award Winners



Over the past 75 years, we at the National MS Society have been through our share of obstacles and crises. But we have never faced a year with the challenges like 2020 presented.

The MS movement remains resilient, and our community's passion and commitment to our shared vision of a world free of MS is inspiring.

The winners of our 2020 Inspiration Awards went above and beyond to keep us moving forward when the world came to a halt. Whether it was finding new ways to bring the MS community together or supporting our mission through their generosity and creative fundraising, we celebrate and honor their dedication to helping every person affected by MS live their best life.



**Dawnia Baynes**

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When the National MS Society began looking for outstanding volunteers to honor for 2020, Dawnia Baynes was an easy choice. She is involved in so many MS Society programs that listing all she does would take far too much space.

She was diagnosed in 2006, but Baynes refuses to succumb to despair and meets every obstacle as an opportunity. In 2017, she created a self-help group for high school and college students. “When I learned there were no groups for that age, I knew I had to fix this problem and I formed MS Youngsters. We meet once a month through Zoom only because of the pandemic and have become an international group.” Despite not yet having children of her own yet, Baynes’s MS Youngsters call her, “MS Mama.”

Never one to sit still for too long, Baynes has begun working on a book about her life and experiences. “I’ve written about 130 pages so far and hope to publish it in 2021 using large type that people can more easily read. I even have ideas for the cover!”



## **Jennifer Frame**

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Jennifer Frame, who has lived with MS for over 30 years, has worn many volunteer hats in the last 12 years: Walk MS® team captain, an MS ambassador at events, support group leader, local office volunteer and MS advocate. Her dedication to the Society’s mission has ensured that no matter what, progress towards a cure continues with force. In 2020, she raised over \$2,000 through Walk MS, engaged in self-help group leader calls to strengthen her support group and showed resilience through personal challenges.

Of her involvement, Frame shares: “I know I am making a difference in small and big ways to spread the word about MS, to support others and myself with MS, and to support those working so hard behind the scenes. I will continue to do all I can to support others with MS

and the awesome team at the Society!”

## **Fundación de Esclerosis Múltiple de Puerto Rico**

The National MS Society depends on global partnerships to continue its progress towards a world free of MS. One of its most crucial partnerships this past year was with the Fundación de Esclerosis Múltiple de Puerto Rico.



## **Fundación de Esclerosis Múltiple de Puerto Rico**

“To be a part of a global MS community means access to a diversity of ideas, programs and better understanding of what is happening worldwide regarding the disease in relation to the new advances,” says Lourdes Fernández Trujillo, executive director at the Fundación.

The Fundación’s motto “Abrazando la Vida,” or Embracing Life, represents how they empower and serve their local, resilient MS community. Through challenges such as Hurricane Maria, earthquakes and the COVID-19 pandemic, the Fundación remained a steadfast pillar of support and education for the Puerto Rican MS community and beyond. They showed exceptional leadership in partnering with the Society for the Ask an MS Expert webinar series to increase access to information.

Trujillo shares: “Having the Society as a partner gives us the opportunity to have access to advocacy professionals who have different experiences and knowledge so we can enrich our programs and services.”

## **Dr. Jaime Imitola**



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As an MS clinician and researcher, Dr. Jaime Imitola, MD, director of the MS Center at UConn Health, University of Connecticut, uses his unique position in healthcare to advocate for patients.

“I have two roles. I go to the lab and try to answer fundamental questions about progressive MS that I see in my patients. When I go to the MS center, I see the societal implications of living with MS and the tremendous gaps in delivery of care and education. My goal is to close the gaps to understand what is needed for optimal MS care” says Dr. Imitola.

He has been involved with the Society for years, launching an MS summit with his local Connecticut Society office to identify unmet needs for patients. He is also a passionate mentor, attracting and training the next generation of MS doctors and scientists. When the COVID-19 pandemic hit, Dr. Imitola was a crucial partner in ensuring the success of the Ask an MS Expert program, where he helped facilitate sessions in English and Spanish. He also worked closely with the local office to identify and advocate for at-risk communities to ensure they had what they needed to get through the pandemic — including orange masks, groceries and organizing mobile COVID testing.

Dr. Imitola hopes to continue his partnership with the Society to empower MS patients and providers. “There is a great gap in the way we deliver care, especially to patients of diverse backgrounds and progressive MS,” he says. “What has helped overcome these challenges is the sense of community we have built and the collaboration with the National MS Society.”

## **Karen Jackson**



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For the last two decades, the late Karen Jackson was a bold and tenacious advocate for the National MS Society — fighting tirelessly to advance public policies to improve the lives of people affected by MS. Jackson passed away in late October 2020.

Despite increasing disability over the years, Jackson never let anything get in the way of participating fully in Society events, including Virginia Action Day in January 2020 and Public Policy Conference in March. She was even known to turn up the speed on her power chair to catch up with members of Congress in the halls of the Capitol. Jackson brought countless supporters to the MS movement and mentored many activists over the years.

In 2020, Jackson was diagnosed with pancreatic cancer. Throughout her treatment she remained steadfastly committed to the MS movement, supporting her friends in Bike MS® and Walk MS, and regularly checking in on her MS activist family. One Society staff member recalls that to continue supporting her fundraising efforts, Jackson gave \$18 to every participant – a symbol in her Jewish faith of “giving chai,” which means giving life. Even through her difficult diagnosis, Jackson continued to ensure that those around her were well.

In her passing, we are reminded of her passion for activism and the profound impact she had on so many in the MS movement.

## **Josh Jacobson**

Josh Jacobson has participated in Bike MS: Ride Across Minnesota for 14 years, raising \$104,000 towards the Society mission to end MS. While he does not have a personal connection to the disease, the cause is deeply personal to him. “I love the cause, but it’s the people who keep me coming back as much as the cause,” says Jacobson. “Even the first year, I was amazed at how friendly everyone was. I resolved then that even if I didn’t ever ride again, I would come back and volunteer.”



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Jacobson has many favorite memories from past races, including three and a half years ago, when his son joined him. But Jacobson's most powerful connection to Bike MS happened off the route, when he lost his girlfriend, a fellow rider and volunteer, in an accident in early 2020. "The outpouring of love I got from the MS society and other riders was amazing," he says. "I got cards and emails. Donations to her race account poured in from volunteers, staffers and other riders. It meant so much."

His resiliency and dedication have shined through the years, and Jacobson plans to do the next Ride Across Minnesota and has already registered for the Twin Cities ride in May. "I will do this race till I'm in my 80s," he says. "And then when I can't ride, I'll volunteer."

## **Scott Kaplan**

Scott Kaplan was diagnosed with MS in 2003 and attended his first Walk MS shortly thereafter. The event was a turning point for him as he was inspired by those he met and realized that while he had MS, MS would not defeat him.

Kaplan captained Team For a Cure every year since that first Walk MS event, raising more than \$260,000 for the Society, of which more than \$170,000 was raised by Scott personally. In addition, he spent countless hours organizing a silent auction which brought in \$10,000-\$15,000 annually.



## **Scott Kaplan**

Driven by the desire to change the courage of MS for himself and for others, as well as motivated by his children – so they'd never have to hear the words, "you have MS." Kaplan took on Bike MS as a cycling novice in 2011. He participated in Bike MS six times over the years and was training for this year's event when he passed from COVID-19 in May 2020.

During Kaplan's final days, he continued to pave the way for others. As his health was declining the week of Walk MS: Denver, those close to him wondered if he'd make it until Walk day so his wife, Denise, challenged friends, family, and strangers to donate to his Walk MS fundraising so that he could be the top fundraiser on walk day. Scott not only got to see the sunrise on Walk day, but he got to do it as the Top Fundraiser. He passed later that day, leaving behind an incredible legacy.

By late September 2020, Kaplan had dropped in the fundraising rankings. Top fundraiser for Walk MS: Denver, Brian Casey, was compelled to make a \$15,000 donation to Kaplan so that he could end the year in the number one spot, proving that the kindness, commitment and resilience of the MS community truly know no bounds. Since his passing, many have shared that Kaplan was their rock when they were newly diagnosed. He demonstrated how to be positive and resilient in the face of MS. He answered questions, provided guidance, and became a role model and inspiration to others.

## **Elissa "EJ" Levy**



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Elissa "EJ" Levy was diagnosed with secondary progressive MS in 2002 and has since dedicated herself to raising awareness and funds for the MS movement.

Levy founded MS Hope for a Cure in 2007, a charitable organization dedicated to raising

funds to help those affected by MS. Since its inception, MS Hope for a Cure has raised over \$10.7 million and funded 138 grants for critical research and programs.

Through MS Hope for a Cure, Levy hosts MS Hope Day which educates others about the disease through a Research and Wellness Symposium and an MS Community Expo. Although this year's event was canceled due to COVID-19, Levy was able to pivot and host BIG October, a virtual event that had an even greater impact through virtual seminars and exhibits.

## **Jon Strum**



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To help address the critical need for timely, relevant information during the COVID-19 pandemic, the National MS Society launched the Ask an MS Expert weekly webinar series. The goal was to provide the latest news on a variety of trending topics while giving those affected by MS a chance to ask questions of MS experts in real-time.

There was only one problem. The series needed a professional moderator.

Society staff members reached out to RealTalk MS podcast host, Jon Strum. Strum graciously accepted this volunteer role, dedicating hours of his time each week to producing the webinar series. Strum continues to do whatever he can to advance the Society's mission and help connect people with MS to the information they need to make informed decisions.

"Having experienced how the destructive force of MS can completely upend a family," Strum said, "I looked for ways to become involved and, perhaps, make another family's journey through the MS jungle slightly less traumatic."

## **Dolores Wolfe**

For her sheer commitment to the cause of raising awareness about MS, Dolores Wolfe is an

inspiration to many people. Now 90 years old, Wolfe has participated in the annual Walk MS in Hershey, Pennsylvania, for more than 30 years, raising nearly \$300,000 for the cause over those decades. The impetus for Wolfe to get involved came in the 1980s when her late daughter was diagnosed with MS. And now, her family has been involved in Wolfe's efforts for years. "There are a lot of people in my family who do the Walks," she says. In fact, four generations of her family have participated with Walk MS, and for the last several years, Wolfe's granddaughter, Janelle Camacho, who also has MS, has helped Dolores continue to join in the Walk by pushing her in a wheelchair.



**Dolores Wolfe (left)**

Not one to seek contributions from big companies, she has done it the old-fashioned way—with personal hand-written notes to the many people she has met over her long lifetime. Dolores is also famous for her pies, particularly her wet-bottom Shoofly and Lemon Sponge pies, and has sometimes made and sold as many as 100 pies.

One might wonder what the source of Dolores's dedication to the MS cause is. "It's simple," she says. "It makes me feel good! And my hope is that I live long enough to see the cure for MS become a reality."

**Lisa McRipley**



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After being diagnosed with MS in 2010 and no longer able to work, Lisa McRipley moved to Michigan, where a sense of empowerment she fostered since a young age led her to become an activist on behalf of others living with MS. “I began volunteering for state and national MS Society programs,” McRipley recalls. She became a volunteer organizer for all five Conferences for African American/Black Families Affected by MS in Detroit, helped organize the Society’s first Black MS Experience Summit and became a trustee for the Michigan chapter of the National MS Society.

As an MS Activist, McRipley says, “I was asked to share my story about dealing with unaffordable MS medications.” That led to her reaching out to Congresswoman Rashida Tlaib of Michigan, who presented McRipley’s story during the U.S. House of Representatives Oversight and Reform Committee’s hearing on drug pricing, where she confronted the CEO of the company about the escalating price of the essential MS medicine, Copaxone.

“When I connected with the people in the MS Society,” McRipley says, “I knew I had found my tribe.”