

Dr. John DeLuca Calls for Action on Rehabilitation Research for Progressive Multiple Sclerosis - Ep24

*** Recorded on May 26, 2021. *** Listen to it here.

JOAN BANKS-SMITH: 00:06 [music] I'm Joan Banks-Smith for Kessler Foundation's spastics research that changes lives. Today, I'm speaking with Dr. John DeLuca, Senior Vice President for research and training at Kessler Foundation. Welcome, Dr. DeLuca.

JOHN DELUCA: 00:21 Thank you. Glad to be here.

BANKS-SMITH: 00:23 In June of this year, you co-authored a peer-reviewed article in the Journal Multiple Sclerosis titled Prioritizing Progressive MS Rehabilitation Research. A call from the International Progressive MS Alliance. For our listeners, the International Progressive MS Alliance is a group of international research experts, representatives from the industry and people affected by progressive MS to devise research priorities for addressing symptoms and progressive MS. Dr. DeLuca, can you tell us a little more about this alliance?

DELUCA: 00:56 The alliance was created several years ago to address the problem of progressive MS. A lot of the research that's been done with MS has been on the relapsing remitting forms of the disease at the expense of progressive forms. And therefore, because the progressive forms of more problems in neurodegeneration, the data collected relapsing remitting may not apply. And so there is a big hole in treating and addressing the issues of progressive MS. This alliance came together, funded by MS societies around the world, to bring people from around the world together to address the specific problems associated with progressive MS.

BANKS-SMITH: 01:44 Based on the results from the MS community, what are the main takeaways of this publication that came out of this alliance?

DELUCA: 01:52 The important thing about this publication is to focus on rehabilitation. 90% of the funding and projects from the Progressive Alliance has gone towards things not associated with rehabilitation. So the purpose of this paper was to outline the importance of addressing four aspects of that particular problems to person with MS have really not been addressed. Those are fatigue, mobility and upper extremity impairment, pain and cognitive impairment. And those four areas, the focus of this paper is the use of rehabilitation to address these issues. And so really the idea was what can and what should the Progressive Alliance do about rehabilitation efforts research in these four areas? And that was the major purpose of this paper, to identify this as a critical need for progressive MS patients.

BANKS-SMITH: 02:53 What is the impact and next implications of this publication to the field?

DELUCA: 02:57 It's going to be an area that is of increased need for funding. The idea that the Progressive Alliance can make this a priority, and therefore, the opportunities for further research for treatment, rehabilitation treatment and persons with progressive MS are really important. Right now, even medications are limited to virtually one medication and only one aspect of progressive MS. So really a lot needs to be done. So this is the first step in this paper to say to the field, "We need more work in

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progressive MS and particularly with rehabilitation." Patients with progressive MS want rehabilitation treatment. We need to know what works, what doesn't work, when it works, and for what. And the hope here is that the Progressive Alliance will be able to provide some of the funding for this kind of research.

BANKS-SMITH: 03:52

Dr. DeLuca, is there anything else that you could share with us, or does that really encapsulates everything?

DELUCA: 03:58

Well, there's a lot to talk about. Progressive MS is just that that people get progressively worse and we need to slow that down and ideally stop that progression. So it's a different way of thinking about MS, that maybe relapsing remitting MS. So because it's really a paucity of work here, we really need to make this a focus. And I think that's what the purpose of this paper is.

BANKS-SMITH: 04:26

Thank you very much.

DELUCA: 04:27

Thank you. My pleasure.

BANKS-SMITH: 04:33

[music] For more information about Dr. DeLuca or to read the Journal article, links are in the program notes. Tuned into our podcast series lately. Join our listeners in 90 countries who enjoy learning about the work of Kessler Foundation. Be sure to subscribe to our SoundCloud channel, Kessler Foundation, for more research updates. Follow us on Facebook, Twitter and Instagram. Listen to us on Apple podcast, Spotify, SoundCloud, or wherever you get your podcasts.