



“Our mission is to spotlight issues that persons with and without disabilities are having NOW because of extreme weather and to foster action to NOW.”

Marcalee and Craig Alexander

Executive Summary

One in 5 people suffer from disabilities; likely someone you know. Meteorological analysis shows extreme weather events, flooding, hurricanes, fires, heat waves and extreme cold spells are increasing in frequency. Persons with disabilities are most vulnerable to extreme weather events; however, they affect all of us. Thus, we must act now to protect persons-with and without disabilities from these dangers.

Canada to Key West is a monumental journey conceptualized after spending over 70 collective years working in rehabilitation. On Summer Solstice 2019, June 21, we will leave our traditional health care jobs to take on a 2350 mile walk from Campobello Island. Our overall mission is to spotlight issues that persons with and without disabilities are having NOW because of extreme weather and to foster collective action to combat climate change NOW. ***The Day for Tomorrow***, the Sunday before autumn solstice is a companion inaugural event designed to have people walk and wheel on an annual basis to highlight this concern. While increasing awareness about the issue of climate change is a long term aim of this mission, in these events we will focus on the acute issue of extreme weather so as to increase public interest in the topic. With this unique approach, as recommended by Marshall¹, we will work to emphasize the urgency of preparing for extreme weather events. Moreover, we aim to create a symbolic moment from which new partnerships between the disability community, the able-bodied community already concerned about climate change, academicians and clinicians caring for persons with disabilities and the general population (who we hope to engaged along the journey and on The Day for Tomorrow) will be forged.

Rationale

The perils of extreme weather and climate change are well documented. In contrast, the vulnerabilities of persons with disabilities to these dangers is often ignored. When there is a public concern, emergency response teams and the media target the masses. As a result, persons with disabilities and the elderly have been disproportionately represented in the number of deaths during catastrophes such as Katrina². There is a 15-minute documentary entitled the Right to be Rescued⁵ by the group Rooted in Rights. Org which provides an excellent portrayal of issues related to disasters for persons with disabilities; but this powerful video has only about 6000 views. This inequality has been addressed in legal cases in the cities of New York and Los Angeles; however, much more work needs to be done to ensure proper care is provided to individuals with disabilities during extreme weather events. Moreover, policies and legislation that address climate change must take into account the special needs of individuals with disabilities.

Realizing that this issue cannot wait for the usual academic approach of research, we are undertaking a unique approach by going straight to communities to discuss the issue. We plan to collaborate with rehabilitation professionals, persons with disabilities, disability-related organizations, the general population and environmental groups along the Canada to Key West route and have expanded to have a national and international collaboration through The Day for Tomorrow. Our hope is this cooperation will promote a shared vision and conviction and collaborative action to protect persons with and without disabilities from extreme weather events. Moreover, we hope to start a movement with

these new partnerships that will ultimately work to address the longer-term issues of sustainability and climate change.

An important value of this walk is the recognition of the saying “Nothing about us without us”. Thus, we are partnering with United Spinal Association to undertake this journey and will partner with academic institutions and community agencies along the way to achieve our specific objectives. Our objective is also to find and highlight heroes along the way who have already experienced the impact of extreme weather events and that are willing to tell their stories.

Specific Goals

1) Increase academicians and clinician’s knowledge and willingness to take action to assist persons with disabilities concerns regarding extreme weather. Little academic attention has been paid to the issues of climate change vulnerability and persons with disabilities⁴. Therefore, we will visit rehabilitation facilities and/or academic medical centers in Boston, New York, Philadelphia, Washington DC, Richmond Virginia and Charleston South Carolina on our walk. At these sites we will put on presentations to professionals about the need to address preparation for extreme weather and climate change with their patients and to embrace these concerns as part of routine health care practices. We will also carry this message to national organizations in the field of rehabilitation by speaking about these issues. We will use information obtained on this journey to revise checklists for persons with disabilities related to disaster preparedness. We are conducting a survey regarding educational needs of clinicians in this topic area and

work to perform a qualitative research study assessing what the key concerns are regarding extreme weather.

2) Increase awareness amongst local governments and individuals about the need for planning regarding the right that persons with disabilities have to be rescued from extreme weather, both now, and in the future. In our city and community sites, we will reach out to the local governments and ask for information regarding their latest plans to protect persons with disabilities from weather extremes. We will disseminate this information to our academic partners, USA affiliates and other appropriate groups and encourage collaboration to assure the plans are sufficiently detailed, are communicated in advance and that persons with disabilities and outside agencies have had an opportunity to review the plans, as per the recommendations in *The Right to be Rescued*.³ We will also disseminate checklists for persons with disabilities that attend our events and make this information available on our website.

3) Increase community collaboration and support for this initiative by developing community teams that are geographically located near target cities for Canada to Key West and nationally and internationally for The Day for Tomorrow. We plan to have people walk or wheel with us locally on in order to develop a shared goal amongst consumers, health care professionals, nonprofit organizations, local governments and the general population about the urgent, tangible need to be prepared for extreme weather for persons with and without disabilities. Considering the length of our journey and the population at our key cities/areas we hope to have 50,000 people walk or wheel with us. Ideally, we would like these individuals to obtain pledges from their friends and families for their miles traversed

and uses these pledges to benefit United Spinal Association with funds specifically targeting future education and work regarding disasters and persons with disabilities. In addition, on the Day for Tomorrow, September 22, 2019 we will ask for people across the country and the world to develop teams and to walk or roll, pledging their mileage to the development of a nonprofit that will provide telehealth services to individuals with disabilities affected by disasters or the local cause of their choice. September 22, 2019 is the day before the UN meeting on climate change in New York and we hope these national groups may bring attention to the need for the UN to include the issues of persons with disabilities in their deliberations. Moreover, as it is symbolically next to autumn solstice we believe this would be an ideal time for a recurrent annual event targeting the issues associate with extreme weather and climate change for persons with and without disabilities.

4) Identify heroes with disabilities and their family members that have suffered from extreme events so they can tell their stories and chronical these stories via social media and a documentary. Through our travel we will seek out persons with disabilities and their family members that can give first-hand accounts of the issues they have dealt with in previous extreme weather events. We will then share these accounts in four ways—via social media during on our walks, through sharing stories via Patient Orator, a video blog that brings attention to health care disparities, through the development of a documentary regarding our walk and the stories of our these heroes with disabilities and through any local and national media attention that we can obtain.

Overall, our emphasis will be on the need to build a narrative of cooperation regarding the issues of extreme weather and climate change for persons with and without disabilities. We seek to do this by bringing together people interested in the concerns of persons with disabilities and those who have no experiences of knowledge of persons with disabilities in shared positive experiences. With both Canada to Key West and The Day for Tomorrow, during events we will address the issues of disasters and the right to be rescued; however, to engage the able-bodied population we will also promote healthy life styles, renewable energy and sustainability.

Communication Plan.

Canada to Key West is the inaugural event in what we hope will be a movement emphasizing the need to act now to protect our communities against the dangers of extreme weather. Our journey is groundbreaking because it a unique approach to targeting an important issue and during our passage we will negotiate the ability to walk on roads, paths, highways, boardwalks and bridges and emphasize the need for our environments to become more conducive to walking or wheeling. Moreover, our means of transportation to academic institutions, patient groups and local communities, to disseminate information, and bring attention to this issue is unique and we hope it will be followed through social media. We will also take the opportunity along the way to highlight cities and towns that are anticipated to be underwater by 2060 and highlight places that have already been impacted by extreme weather. During the Day for Tomorrow we will bring our mission and our message to a national and international audience. Because we will be walking and are inviting participants with a cause, it is envisioned that 50,000 people may walk or wheel

with us during these events. Ideally, people that form teams for the Day for Tomorrow will have 200 people participating in these events and they will walk for 7 km to symbolize the 7 continents and the fact that this is a crisis without borders. However, to insure inclusivity people will be able to travel as short or as long as they like as our overall goal is to maximize participation in the mission. Our overall goal is to make this a positive, life-changing activity for participants where they can enjoy their contribution while seeing the need to take action now and work in tandem to be prepared for extreme weather events.

Through strategic partnering we plan to have United Spinal Association and our academic partners promote the walk through all of their regular channels including social media, Facebook, Twitter, Instagram and other routine means of promoting their organizations and missions. We anticipate all will use the journey logo so we can achieve greater recognition for Canada to Key West and The Day for Tomorrow.

We will promote the journey through the development of a Facebook page and website and to actively engage people through Instagram, and Twitter. We will launch Canada to Key West four months prior to its start at the Association of Academic Physiatrists meeting on February 21, 2019. Along the journey we will take and post images of the people we speak with and the places we go. In addition, a unique component of the movement will be the use of video oration regarding our champions with disabilities and the development of a documentary chronicling the experience. Finally, we will work to provide lectures at professional meetings, write two academic papers and disseminate check lists regarding extreme weather both at our local sites and via our website. All of these methods are easily tracked, thus evaluation of our outcomes with these objectives will be streamlined.

Management

Marcalee Alexander will take the lead in planning and organizing this journey. She and her husband, Craig Alexander will donate their time. Patricia Duncan will serve as project coordinator. Complete budget information for both events is available on request.

Mapping the Walk-preliminary calendar

The journey will begin on the Summer Solstice at Campobello Island in Canada. During this journey we will intermittently travel the coast line, visiting communities that have already been impacted by extreme weather events but also visiting many of the communities expected to be partially underwater in 2060. We will also stop and spend time at different cities along the way to interact with city personnel and advocate that persons with disabilities are involved in disaster planning and that there is targeted and appropriately disseminated support for persons with disabilities when disasters occur. Our plan is to ultimately complete the expedition in Key West, Florida, the southernmost city in the US approximately 9 months after the start or by March 30, 2020.

Dynamic Schedule--eApproximate Date	Event
February 21, 2019 Association of Academic Physiatrists MeetingR	Event Launch
June 21 Campobello Island, Canada Lubec, Maine	Journey Begins
July 22 Boston, Spaulding Rehabilitation	Academic Event
August 13 Mt. Sinai, New York	Academic Event
August 14 Hoffstra Northwell Manhasset, Long Island	Academic Event
August 14	Walk to Manhattan from Long Island-Community Walk
August 15 Columbia University, NYC	Academic Event
August 16 New York University, NYC	Academic Event
August 17, 18 Walk around New York City	Community Walk
August 29-September 1 Atlantic City Area	Live Streaming
September 9-11 Jefferson Medical College Philadelphia, PA	Academic Event
September 20 National Rehab Hospital Washington, DC	Academic Event
September 22 Washington DC	The Day for Tomorrow
October 1, Virginia Commonwealth University Richmond, Virginia	Academic Event
October 10 Rocky Mount, North Carolina October 17, Fayetteville North Carolina October 26, 2019\ Myrtle beach, south carolina	Live Streaming
October 28-November 8 iscos meeting	Academic Presentation by Drs. Alexander
November 9 resume walk Myrtle Beach, South Carolina	
November 18 Charleston, South Carolina	Academic Event

November 28, Hilton Head	Live Streaming
December 4 Tybee island Georgia	Live Streaming
December 18, Cumberland Island, Georgia	Live Streaming
December 28, Jacksonville Beach, Florida	Live Streaming
Mid February South Florida	Academic Event
Mid-End of March 2020	Final Event Key West Florida

Appendix A: Recommendations from The Right to Be Rescued regarding Emergency

Planning

1) There must be detailed plans that anticipate the needs of PWD and outline clear strategies for meeting these needs.

2) Cities must provide effective, detailed communication with people with disabilities before, during and after emergency events.

3) Cities should enlist outside experts to assist with modifications to emergency plans.

4) PWD must be allowed to meaningfully participate in emergency planning processes.

References

1) Marshall, G. Don't Even Think About It: Why our brains are wired to ignore climate change. 2014 Bloomsbury Publishing. USA

2) EPA fact sheet. Climate change and the health of people with disabilities. EPA-430-F-16-060 May 2016

3) Weibgen, A. The right to be rescued: Disability justice in an age of disaster. The Yale Law Journal; 2015; 2406-2469.

4) Gaskin CJ, Taylor D, Kinnear S, Mann J, Hillman W, Moran M. Factors associated with climate change vulnerability and the adaptive capacity of people with disability: A systematic review. Weather, Climate and Society. Oct 2017. 801-814.

5) The Right to be Rescued by Jordan Melograna accessed 12/11/2018 at <https://www.rootedinrights.org/righttoberescued/>