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| Updates from the CF Foundation Western New YorkApril 2020 |

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| **Keep in touch virtually!****ResearchCon - 4/16/20**ResearchCon is a free, virtual event that will focus on the next era of the cystic fibrosis transmembrane conductance regulator (CFTR) science and genetic-based therapies.  Researchers, clinicians, and community members will give live presentations and answer questions on understanding a wide variety of topics including: therapies for rare and nonsense mutations, health effects of highly effective CFTR modulators, the effects of modulators and how to reduce treatment burden, reproductive health related to modulators, potential genetic-based therapies to fix or replace CFTR protein, and how the CF community can engage and partner in research in this exciting new era.ResearchCon will begin at 6:30pm and end at approximately 10:45pm.  The event is open to anyone 16 or older with a personal or professional connection to CF.  [Learn more and register now!](https://urldefense.proofpoint.com/v2/url?u=https-3A__t.e2ma.net_click_z64yjc_jivqen_vf90xn&d=DwMFaQ&c=4sF48jRmVAe_CH-k9mXYXEGfSnM3bY53YSKuLUQRxhA&r=Wxhiij1yf6IFmJ6Oxuov4pqaTobdfHBNWzusX8cda_4&m=TcKCVN19rthYNd5SpDIZpz17pspw5t1r4DDga6gzY2k&s=jffVheOmJgGt2r-CYzXCjGQ1HoX1NvJbEqyL9JX2kmQ&e=)**Gratitude Hour - 4/22/20**Join us online on Wednesday, April 22 from 7-8:00 pm ET as we virtually come together as a community to share thanks during National Volunteer Week. Hear from adults with cystic fibrosis, family members and care team members on what they’re thankful for, and share your gratitude with everyone that is helping to make CF stand for cure found.  [Register here.](https://urldefense.proofpoint.com/v2/url?u=https-3A__t.e2ma.net_click_z64yjc_jivqen_b890xn&d=DwMFaQ&c=4sF48jRmVAe_CH-k9mXYXEGfSnM3bY53YSKuLUQRxhA&r=Wxhiij1yf6IFmJ6Oxuov4pqaTobdfHBNWzusX8cda_4&m=TcKCVN19rthYNd5SpDIZpz17pspw5t1r4DDga6gzY2k&s=xZtHIjO1we3j_R7tR2MNiiajtiOUgT6GKZaXC3PEIN0&e=)**Virtual Great Strides - 6/5/20**Save the date for a national, virtual Great Strides walk and celebration of the CF Foundation's 65th anniversary on Friday, June 5th.  This 65 Roses Day join us, and thousands of others from the CF community, to celebrate 65 years of progress.  If you were already registered for a Great Strides walk you don't need to do anything.  You can remain registered for your walk and still participate in the virtual walk on 6/5.  Please [stayed tuned to our Facebook page](https://urldefense.proofpoint.com/v2/url?u=https-3A__t.e2ma.net_click_z64yjc_jivqen_r0a1xn&d=DwMFaQ&c=4sF48jRmVAe_CH-k9mXYXEGfSnM3bY53YSKuLUQRxhA&r=Wxhiij1yf6IFmJ6Oxuov4pqaTobdfHBNWzusX8cda_4&m=TcKCVN19rthYNd5SpDIZpz17pspw5t1r4DDga6gzY2k&s=lUgAHxB-J6a3wZfuTz65_ddyHkiUB-si1XWpDbC711E&e=) for more virtual opportunities that become available!The WNY Chapter is going to start featuring our local CF Community on Social Media!  Our Western New York, Cystic Fibrosis Foundation Facebook page is going to start 2 fun segments; “Two Minute Tips” and “My Favorite Things”.  We’d love to hear from you and if you would like to help us with a facebook video, contact Sara Spider at (716)204-2535 or sspider@cff.org. |

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| **Volunteer Leadership Conference**We hope many of you were able to tune into our Volunteer Leadership Conference last month!  Highlights included stories from people on the importance of their "CF squads", recognition of our volunteer leadership council, and research and medical updates by a panelist of doctors including our CEO, Mike Boyle.If you were unable to attend, you can still [watch the archives here](https://urldefense.proofpoint.com/v2/url?u=https-3A__t.e2ma.net_click_z64yjc_jivqen_7sb1xn&d=DwMFaQ&c=4sF48jRmVAe_CH-k9mXYXEGfSnM3bY53YSKuLUQRxhA&r=Wxhiij1yf6IFmJ6Oxuov4pqaTobdfHBNWzusX8cda_4&m=TcKCVN19rthYNd5SpDIZpz17pspw5t1r4DDga6gzY2k&s=XB9wAGONi96Kgc5vhglIAD420PEu1DvTvout3NffdhQ&e=). |

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| **Great Strides**We would like to extend an invitation to all walkers to attend our Letchworth Great Strides walk scheduled for Sunday, September 20.  The walk takes place at Letchworth State Park and registration begins at 11:00am.  You do not need to register for this event to attend.  Please just contact your walk coordinator to let them know or call us at the office at (716) 204-2535.  There is an admission fee, but if we know you're coming by Wednesday, September 16th, we can have your name on the list and admission is free!  Please contact us with any questions and we hope to see you all there!  |

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| **Finest and Rising Stars**We are now accepting nominations for Rochester's Finest and WNY's Rising Stars!  These philanthropic leadership programs recognize young professionals, ages 21 to 40, who are leaders in their work and community.  Nominate an individual for Rochester's Finest [here](https://urldefense.proofpoint.com/v2/url?u=https-3A__t.e2ma.net_click_z64yjc_jivqen_nlc1xn&d=DwMFaQ&c=4sF48jRmVAe_CH-k9mXYXEGfSnM3bY53YSKuLUQRxhA&r=Wxhiij1yf6IFmJ6Oxuov4pqaTobdfHBNWzusX8cda_4&m=TcKCVN19rthYNd5SpDIZpz17pspw5t1r4DDga6gzY2k&s=G07EkNN19pZGUC1dR9R7mNB7OWyR0GsET_FK0r-jqEw&e=).Nominate an individual for WNY's Rising Stars [here](https://urldefense.proofpoint.com/v2/url?u=https-3A__t.e2ma.net_click_z64yjc_jivqen_3dd1xn&d=DwMFaQ&c=4sF48jRmVAe_CH-k9mXYXEGfSnM3bY53YSKuLUQRxhA&r=Wxhiij1yf6IFmJ6Oxuov4pqaTobdfHBNWzusX8cda_4&m=TcKCVN19rthYNd5SpDIZpz17pspw5t1r4DDga6gzY2k&s=zDLOxIzVe2Fa0_aBfNNLsywAao75P0315u6k_IyacLU&e=). |

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| **Community Voice**Community Voice is our go-to group of over 1,000 people who have signed up to participate in non-fundraising CF-related projects.  This group provides the opportunity for people affected by CF to take an active role in shaping the resources that are being developed for them and the rest of the CF community.  Each person's experience is valuable and every perspective should be heard.  The members of Community Voice have been instrumental in the development of various clinical care, research, and CF community programs.  The program is open to adults with CF and their family members including parents, siblings and spouses.  Members can choose how much they participate.  The majority of asks that go out to the group are surveys, focus groups and requests for applications for committees and advisory groups.If you're interested in joining please visit [cff.org/communityvoice](https://urldefense.proofpoint.com/v2/url?u=https-3A__t.e2ma.net_click_z64yjc_jivqen_j6d1xn&d=DwMFaQ&c=4sF48jRmVAe_CH-k9mXYXEGfSnM3bY53YSKuLUQRxhA&r=Wxhiij1yf6IFmJ6Oxuov4pqaTobdfHBNWzusX8cda_4&m=TcKCVN19rthYNd5SpDIZpz17pspw5t1r4DDga6gzY2k&s=9fdxUQTODepNukN8oR6GxJlwXofcNUy6eotXBoCY6fo&e=) or contact them at communitvoice@cff.org. |

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| **Putting the TEAM in TEAMMATE**Please contact any of the staff at the Western New York Chapter with questions regarding information in this newsletter.  Thank you for all you do!* Heather McKeever, Executive Director
	+ hmckeever@cff.org
* Jessica Miller, Operations Specialist
	+ jmiller@cff.org
* Carolyn Nerber, Senior Development Director
	+ cnerber@cff.org
* Lauren Orlowski, Development Manager
	+ lorlowski@cff.org
* Patty Schwarzweller, Associate Executive Director
	+ pschwarzweller@cff.org
* Sara Spider, Event Support Specialist
	+ sspider@cff.org
* Kelly Tronolone, Development Director
	+ ktronolone@cff.org
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| **Covid-19 Updates**CF Foundation staff are working and available during the corona virus outbreak.  While all in person events have been cancelled through June 30, we are still committed to our mission and will be sharing virtual opportunities and ways for our community to stay connected.  Please follow our [local Fa](https://urldefense.proofpoint.com/v2/url?u=https-3A__t.e2ma.net_click_z64yjc_jivqen_zye1xn&d=DwMFaQ&c=4sF48jRmVAe_CH-k9mXYXEGfSnM3bY53YSKuLUQRxhA&r=Wxhiij1yf6IFmJ6Oxuov4pqaTobdfHBNWzusX8cda_4&m=TcKCVN19rthYNd5SpDIZpz17pspw5t1r4DDga6gzY2k&s=EpFCq64SYJPs_Fv00iACFac_bhcmCCBu6ajEw5Z15C0&e=)[cebook page](https://urldefense.proofpoint.com/v2/url?u=https-3A__t.e2ma.net_click_z64yjc_jivqen_frf1xn&d=DwMFaQ&c=4sF48jRmVAe_CH-k9mXYXEGfSnM3bY53YSKuLUQRxhA&r=Wxhiij1yf6IFmJ6Oxuov4pqaTobdfHBNWzusX8cda_4&m=TcKCVN19rthYNd5SpDIZpz17pspw5t1r4DDga6gzY2k&s=reKn85AX5R2tUkFZDcRRLS27mW6eEbjjX6Ds7o08Eb8&e=) to check those opportunities out.The CF Foundation has prepared FAQ's to address key concerns from our CF community.  You can [read those FAQ's here](https://urldefense.proofpoint.com/v2/url?u=https-3A__t.e2ma.net_click_z64yjc_jivqen_vjg1xn&d=DwMFaQ&c=4sF48jRmVAe_CH-k9mXYXEGfSnM3bY53YSKuLUQRxhA&r=Wxhiij1yf6IFmJ6Oxuov4pqaTobdfHBNWzusX8cda_4&m=TcKCVN19rthYNd5SpDIZpz17pspw5t1r4DDga6gzY2k&s=PGCIWRvhXI_7kepLzmLtb_LAPsr2IdMl90QrquAg8O8&e=). |

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**Rochester CF Cycle for Life**July 18, 2020CF Cycle for Life is a fully-supported ride with route options of 10, 35 and 65 miles all starting at 8:00am.  From breakfast to our cycle post party, you can enjoy fully stocked rest stops every 10-12 miles, bike mechanics for bicycle maintenance and repair, ride marshalls to cheer you along the way and plenty of support vehicles to help you complete the ride.  Contact Patty Schwarzweller at pschwarzweller@cff.org for more info. |

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**65 Roses Golf Tournament**August 10, 2020Join the Western New York Chapter of the CF Foundation for the 8th Annual 65 Roses Golf Tournament.  This fun and friendly tournament will be an opportunity for supporters of those living with CF to come together and "swing a club for a cure."Contact Kelly Tronolone at [ktronolone@cff.org](https://urldefense.proofpoint.com/v2/url?u=https-3A__t.e2ma.net_click_z64yjc_jivqen_r4h1xn&d=DwMFaQ&c=4sF48jRmVAe_CH-k9mXYXEGfSnM3bY53YSKuLUQRxhA&r=Wxhiij1yf6IFmJ6Oxuov4pqaTobdfHBNWzusX8cda_4&m=TcKCVN19rthYNd5SpDIZpz17pspw5t1r4DDga6gzY2k&s=pHZAdNQnS2WLq9Eco_jgfiPIen8JQWLk8IQSPyxFhso&e=) for more info. |

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**How Can Compass Help You?**Find out [here](https://urldefense.proofpoint.com/v2/url?u=https-3A__t.e2ma.net_click_z64yjc_jivqen_npj1xn&d=DwMFaQ&c=4sF48jRmVAe_CH-k9mXYXEGfSnM3bY53YSKuLUQRxhA&r=Wxhiij1yf6IFmJ6Oxuov4pqaTobdfHBNWzusX8cda_4&m=TcKCVN19rthYNd5SpDIZpz17pspw5t1r4DDga6gzY2k&s=jizu5_1DQt-qlt1RYxCreG9BKu-lEKDHQiqj3fMFdd4&e=). |

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| **Advocate With Us**Your voice has the power to inspire action and help shape public policy. Learn more about how you can help make a difference in the mission to cure CF.To sign up for advocacy alerts text FIGHTCF to 96387.  Learn more [here](https://urldefense.proofpoint.com/v2/url?u=https-3A__t.e2ma.net_click_z64yjc_jivqen_3hk1xn&d=DwMFaQ&c=4sF48jRmVAe_CH-k9mXYXEGfSnM3bY53YSKuLUQRxhA&r=Wxhiij1yf6IFmJ6Oxuov4pqaTobdfHBNWzusX8cda_4&m=TcKCVN19rthYNd5SpDIZpz17pspw5t1r4DDga6gzY2k&s=qxsJ_tp3R37WHNfZNwTaBmpupl8-rL1FSt1Awl4ucYY&e=). |

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| **Mission**The mission of the CF Foundation is to cure cystic fibrosis and to provide all people with CF the opportunity to lead long, fulfilling lives by funding research and drug development, partnering with the CF community and advancing high-quality, specialized care. **A copy of the latest annual report may be obtained from the organization or from The Charities Bureau, Department of Law, 120 Broadway, New York, NY 10271.**The Cystic Fibrosis Foundation has unrestricted financial reserves of about 10 times its budgeted 2019 annual expenses, following a one-time royalty sale in 2014.  These funds, along with the public's continuing support, are needed to help accelerate our efforts to pursue a cure for this fatal disease, fund development of new therapies, and help all people with CF live full, productive lives.  Obtain a copy of our latest Annual Report [here](https://urldefense.proofpoint.com/v2/url?u=https-3A__t.e2ma.net_click_z64yjc_jivqen_jal1xn&d=DwMFaQ&c=4sF48jRmVAe_CH-k9mXYXEGfSnM3bY53YSKuLUQRxhA&r=Wxhiij1yf6IFmJ6Oxuov4pqaTobdfHBNWzusX8cda_4&m=TcKCVN19rthYNd5SpDIZpz17pspw5t1r4DDga6gzY2k&s=TDJH1QwfiyvvgMSJ6rEw8yzDXVTN5c6OQekv0bWVU_g&e=), email info@cff.org or call 1800-FIGHT-CFF. |

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| **Important Note on Attendance at Foundation Events**The Foundation is closely following the evolving coronavirus outbreak.  We will continue to monitor [coronavirus guidance](https://urldefense.proofpoint.com/v2/url?u=https-3A__t.e2ma.net_click_z64yjc_jivqen_z2l1xn&d=DwMFaQ&c=4sF48jRmVAe_CH-k9mXYXEGfSnM3bY53YSKuLUQRxhA&r=Wxhiij1yf6IFmJ6Oxuov4pqaTobdfHBNWzusX8cda_4&m=TcKCVN19rthYNd5SpDIZpz17pspw5t1r4DDga6gzY2k&s=hRqiyxzmkwRYFOd7rHcShe5dy0V8_C8HSS2GM2h6qsU&e=) from the Centers for Disease Control and Prevention and assess whether we need to change any scheduled events.  To reduce the risk of getting and spreading germs at CF Foundation-sponsored events, we ask that everyone follow basic best practices by regularly cleaning your hands with soap and water or with an alcohol-based hand gel, covering your cough or sneeze with a tissue or your inner elbow and maintaining a safe 6-foot distance from anyone with a cold or infection.  Medical evidence shows that germs may spread among people with CF through direct and indirect contact, as well as through droplets that travel short distances when a person coughs or sneezes.  These germs can lead to worsening symptoms and speed decline in lung function.  To further reduce the risk of cross-infection, the Foundation's attendance policy recommends invititing only one person with CF to an indoor Foundation-sponsored event at a specific time.  For an outdoor event, the Foundation recommends that all people with CF maintain a safe 6-foot distance from each other at all times.  |

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| Cystic Fibrosis Foundation - WNY100 College Parkway, Suite 280Williamsville, NY 14221716-204-2535west-ny@cff.org |

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| [www.cff.org](https://urldefense.proofpoint.com/v2/url?u=https-3A__t.e2ma.net_click_z64yjc_jivqen_r8o1xn&d=DwMFaQ&c=4sF48jRmVAe_CH-k9mXYXEGfSnM3bY53YSKuLUQRxhA&r=Wxhiij1yf6IFmJ6Oxuov4pqaTobdfHBNWzusX8cda_4&m=TcKCVN19rthYNd5SpDIZpz17pspw5t1r4DDga6gzY2k&s=8Jo5d17YQTJ4czXNtQCKvp_PFobsvbqY5owzyMSc6mg&e=)/westernny |
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