

MUSELLA FOUNDATION FOR BRAIN TUMOR RESEARCH & INFORMATION, INC

2022 HIGHLIGHTS

Patient Navigation Program / Brain Tumor Learning System

The major projects of 2022 include taking our patient navigation system to the next level with the help of our partners at Cancer Commons and xCures.

The major changes to the system include the participation of more world class neuro-oncologists, and advances to the software automation and artificial intelligence that run the system. We now have the ability to acquire a patient's medical records and process them into a patient journey in about 15 minutes, when it used to take a week or two! (Thanks to xCures!). We had over 1,000 brain tumor patients go through the process and we were overwhelmed resulting in delays. Now we can handle a larger number of patients, and process updates faster than ever before and we continue to improve automation and artificial intelligence of the system!

Copayment Assistance Program

Donations to our programs have not yet rebounded from the pandemic. We awarded copayment assistance grants totaling over \$1.3 million to 268 brain tumor patients so far this year (as of 11/1/22), which is a little less than last year's numbers of \$1.4 million for 297 patients. Unfortunately, this completely eradicated all of our reserves for the program. We had to close our program to new patients for almost half the year; had funding been available, we would have been able to help so many more families. This is a life saving program. Many of these patients told us they would not have been able to get access to their treatments without our help. While we were closed, we heard heartbreaking stories every day of patients forgoing treatments.

Research

So far this year, we gave out \$505,000 in research grants by ourselves, and another \$198,000 grant in conjunction with the DIPG collaborative. Last year, we managed to give \$427,000. As always, we made the best use of the money we had, and this was an especially exciting year for research projects. All of the projects we fund are extremely worthy. In this year's group we have a few projects that may have a good chance to lead to breakthroughs. You can find details on our website at <https://virtualtrials.org/Grants.cfm>.

We have a track record of picking important early projects. A few of our earlier grants are paying off big time. We played a role in what looks to be the next two treatments to get FDA approval.

Back in 2004 and 2005, we gave grants to Dr. Linda Liau in the amount of \$200,000 for work on her brain tumor vaccine project, which is now called DC-Vax. Results of the phase 3 trial were recently released (<https://virtualtrials.org/dcvax.cfm>) showing impressive results with both newly diagnosed as well as recurrent Glioblastoma. Hopefully, the vaccine will be approved soon by the FDA.

The most promising experimental treatment for DIPG and DMG in both children and adults is a drug called Onc-201. Back in 2014, we gave a grant to Dr. Josh Allen to work on this drug. Since then, we gave a total of 7 grants totaling \$875,000 (part of which was donated to us from other foundations - see virtualtrials.org/grants.cfm for details) for work on this drug. We also helped

run the expanded access program for this drug where we treated 133 patients and had some absolutely miraculous responses. We reported the preliminary results in a poster at SNO recently. Hopefully, the drug will receive FDA approval soon, so it can help more patients.

Advocacy

Along with a few other organizations, we helped author a bill titled the “**Promising Pathway Act,**” which was introduced into Congress by Senator Braun (R-Ind). This bill will drastically speed up the search for the cure for not only brain tumors, but most serious incurable diseases. The bill should also hold down the cost of new drugs, make access faster and easier, and drastically increase the amount of research being done to find treatments! This is one of the most important bills for you to help support, as it can produce results to help people who are already diagnosed with these diseases as well as those who will be diagnosed in the future. For more information, go to virtualtrials.org and click on the “**ACTIVISM ALERT**” for a quick and easy way to write your representatives! The FDA has decided to make the Accelerated Approval pathway much harder to use and it will now take a few more years and lots of money to use that pathway – this will reduce our access to new treatments, and my bill is one way to fix that. We are also working on another way to fix it!

Brain Tumor Guide For The Newly Diagnosed

We published the new Twelfth Edition of our Brain Tumor Guide. This was a major rewriting of the entire guide. We took suggestions from our readers and added a lot more detail to some topics and added a lot of new topics. The size of the book went from 138 pages to 369 pages. Brain tumor patients and/or their caregivers really should know everything in this book in order to make the best decisions and understand their disease better. The book is literally life saving. As always, we offer it free on the website as an e-book, or you can order a free printed copy. Due to runaway inflation, as well as the size increase in the book, the cost to print and mail a copy of the book has increased about 7 times what it cost to send out the last Edition.

Collaborations

We are all about collaborating. Working together as an army is way more effective than each organization trying to do it alone. We are active members of the following collaborations: xCures and Cancer Commons – for the xINFORM program and the Patient Navigation Program! We are foundational partners of the Children’s Brain Tumor Network, the DIPG / DMG Collaborative and the DIPG all-in-initiative. We are members of the Jumpstarting Brain Tumor Drug Development Coalition and participate in many collaborative meetings with other brain tumor organizations.

About Donations

We understand that some people prefer their donations to go solely to research, and do not want them to be used for salaries, overhead, direct patient assistance, educational programs and materials. Therefore, when donating online, we allow you to select how your donation will be used. ***If you select “Research Only,” (or do not make any selection) 100% of your donation will go to research.*** If you select “Co-pay program,” 91% of your donation will go to patients who need assistance, and the remaining 9% goes to the cost of running the program. If you select “Unrestricted,” you afford us the most flexibility to use the money where it is most needed.

We have so many vital and urgently needed projects just waiting for funding. But we can only do it with your help. Can we count on you to help the Foundation support the development of new, improved treatments and therapeutics while assisting those who struggle with the ravages of brain tumors? We only send out this one appeal to you for the year, and are very grateful for your generosity. For those who have benefited from our services, we ask that you tell your friends how important our services have been to you and your family and suggest they consider donating in your honor.

Thank you for your consideration of the needs of community we serve, and we look forward to continuing the fight against brain tumors with you in the year to come.

Feel free to call us at 888-295-4740 or email musella@virtualtrials.org if you would like to talk about how we will use your donation!