

**Musella Foundation for Brain Tumor Research & Information, Inc**  
**2021 Highlights**

**Patient Navigation Program / xINFORM**

The major projects of 2021 include taking our Brain Tumor Virtual Trial and the Patient Navigation program to the next level with the help of our partners at Cancer Commons and xCures.

xINFORM was launched! This is a patient portal where our patients can submit their medical records, and get a fantastic graphical representation and summary of their medical history. They get access to a report showing a list of the best treatment options for their specific case. We track the treatments patients undergo and their outcomes. We follow their case longitudinally, so we always have their medical history up to date. When circumstances change, such as a progression of the tumor, or updated biopsy results, a new report can be generated to reflect those changes.

xINFORM may eventually replace our Brain Tumor Virtual Trial project. It is more validated, as it uses medical records instead of just patient reporting. All patients' records get added to this new database, which is called XCELSIOR. The artificial intelligence system created by xCures learns from every patient so it gets better with time and patient volume. This all comes together as a clinical trial: NCT03793088: A Patient-Centric Platform Trial for Precision Oncology. We are trying to prove that our approach results in much better outcomes than randomly choosing a clinical trial or using only the standard treatment.

xINFORM forms the basis of our Patient Navigation Program. xINFORM collects and collates the medical histories, and creates the options report quickly. For some patients, that is all that is needed. For others who want or need more help, we (the Musella Foundation and Cancer Commons) also offer a "deeper dive" where we can manually fine tune the options report, help you understand the options, and help you get access to the treatments. While these services are expensive to offer, as of now, there is no cost to our patients; we rely on donations to support it. If we can't raise enough donations, there may be a charge to patients who register in the future. For details or to join the project go to [Virtualtrials.org/xcelsior.cfm](https://Virtualtrials.org/xcelsior.cfm)

Note that we are focused on brain cancer, but the Cancer Commons and xCures team handle just about all types of advanced cancer, with special emphasis on pancreatic, ovarian, colon and bladder cancers.

**Copayment Assistance Program:**

Due to the pandemic, donations to all patient assistance programs slowed down. We had our busiest year ever - awarding over \$1.4 million to 297 brain tumor patients so far this year (as of 10/1/21), which is more than any previous entire year! 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:**

Again, due to the pandemic, donations were slow. So far this year we gave out \$402,000 in research grants. Last year we managed to give \$500,292. 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>.

## 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](http://virtualtrials.org) and click on the “**ACTIVISM ALERT**” for a quick and easy way to write to your representatives!

## 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.

## Publications

Our president, Al Musella, DPM had 2 papers published this year and 2 poster presentations:

“*Virtual Trials: Causally-validated treatment effects efficiently learned from an observational cancer registry*” medRxiv <https://doi.org/10.1101/2021.06.12.21258409>

“*The Importance of Shared Decision-Making for Patients with Glioblastoma*” in Patient Preference and Adherence, October 2021.

*A Multilevel Model For Precision Oncology* Poster at Prob Prog 2020  
<https://www.xcures.com/content/uploads/2020/10/202010-xC-Poster-ProbProg-A-multilevel-model-for-precision-oncology.pdf>

“*XCELSIOR: A real-time, real-world learning platform for patients with advanced cancer*” was presented as a poster at SNO 2021.

## 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, educational programs and materials. Therefore, when donating online or with the attached donation form, we allow you to select how your donation will be used. ***If you select “Research Only,” 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.

Feel free to call us at 888-295-4740 or email [musella@virtualtrials.org](mailto:musella@virtualtrials.org) to discuss making larger gifts of appreciated stocks, retirement assets or naming us in your will.