

ABTA Session: Who We Are

- Ralph DeVitto, ABTA President and CEO
- Nicole Willmarth, PhD, ABTA Chief Mission Officer
- Brandon Starkoff, Chair of ABTA Board

Mr. DeVitto: Hello again and how about Nadia and our Patient Services Team?

[Applause.]

Mr. DeVitto: Again, thank you for all of you for joining us both in person and in Livestream. This is a new, session for the National Conference. We had realized that one thing we didn't do a good job of is taking a little bit of time to share who we are, what we do at the American Brain Tumor Association. So the next 30 minutes will be a brief overview of our mission, our approach to our mission, Nicole will talk to you about our Patient Service Program, the Research Programs. And then Brandon Starkoff, who is a brain tumor survivor and the chair of our board, will talk to you about how you can join us and have an impact.

And those of you Livestreaming, do not hesitate to reach out to us in the coming weeks with your input. Erin and Jeffrey, thank you for your comments about the evaluation. I just want to reinforce that. This is a conference for the brain tumor patient and caregiver and we listen and this is a brand-new session, because we've heard from you that you want to know a little bit more about the ABTA. This is again, 30 minutes. So ABTA.org is all things American Brain Tumor Association. ABTA.org.

Those are the three of us that are speaking. We can go to the next slide. No. It worked earlier. We have a picture of some grapefruit.

[Laughter.]

Okay. Here we go. Thank you, Nicole. Her PhD must be in engineering. I thought it was -- okay. So, briefly what we're going to do is an [sic¹] overview of the ABTA. You'll hear from Nicole about our research patient services program and then Brandon will talk to you about how you can have an impact.

And so I was talking earlier about our wonderful two co-founders; Susan Kramer and her husband, Manny, will be here later on this morning. So I hope you take a moment to meet her, listen, learn, share with her your interaction with the ABTA. She'll be here all day today and tonight. And so you think back to 1973 and what the landscape looked like. I mean, it was starkly different than it is today and I am proud of the fact that today we do have more resources to support the patient going through the horrific experience; the caregivers to support them.

You heard from Vince earlier, when you were introduced to Vince Rock, our team is here to support you through every step of the way. We did not have national programs. We didn't have a national commitment to brain tumor research as we do today.

Is it where we want it to be? No, but the progress we have made -- Jeffrey talked about this conference, in two years, how [sic] the progress we have made at this conference in two years -- how the progress we have made. Think back to the landscape that was, that is, and together we're going to make it even better and provide more services, more support and more brain tumor research than we have.

¹ [sic] is used to denote the typed material was transcribed exactly as spoken.

The mission of the American Brain Tumor Association is for us to advance the understanding and treatment of brain tumors. And we want the patient experience to be improved, to extend and ultimately to save the life of those diagnosed with a brain tumor.

And we do it through two primary ways. The American Brain Tumor Association is a leader in direct and referral of brain tumor patient and caregiver support. You'll be hearing about what we do with a lot more information available either in conversation or online. And in addition, our legacy is brain tumor research.

And it is open call -- meaning the best scientists with the best ideas can present them and then we have panels of volunteer researchers who do a process of reviewing, ranking and then presenting to our Board of Directors recommendations on what to fund.

The more money we raise, the more researchers we can fund. Primarily in the U.S, but also in institutions around the country [sic]. Our mission is very straight-forward. It is all about making a difference in this fight. We ask you to join us, you'll hear more about it.

And so you will see that we have a multifaceted approach that was primarily focused on the brain tumor patient, the caregiver. What can we do? We never rest. We continually ask ourselves -- and Nadia, being new as our Director of Patient Services -- is bringing a fresh perspective about what we're currently delivering. What can we do differently? For example, we're moving into a much more significant way, the whole issue of brain metastasis. Because we know there 2-400,000 people a year whose primary tumor, then unfortunately, moves to the CNS and so we have a whole host of opportunities to work with more people. As we learn more about it, work with health care professionals, work with patients directly and their caregivers as

we go through that journey.

But we are proud of what we do in directly serving you, the brain tumor patient and you the brain tumor patient caregiver, and we are proud of the research that we are funding. Both the next generation of newer researchers and those that are in their career moving towards more and more great fruits [sic].

So next, you're going hear from Nicole who will tell you more about the ABTA mission.

[Applause.]

Dr. Willmarth: Thank you, Ralph. Welcome everybody, good morning. My name is Nicole Willmarth, as Ralph just said, and I'm the Chief Mission Officer at the ABTA and I'm very happy to be here today to tell you guys a little bit more about our mission and action.

Ralph gave a very good overview of our mission and I'm going to show you in a little bit more detail about our research program as well as our patient services and support.

I'm going to start with research. For research we have two main priorities I would say. One is to foster a new generation of scientists to discover the causes, effects, diagnosis and treatment of brain tumors. And another is to fund high-risk, high-impact, innovative research with the potential to change paradigms.

And I have a list of some of the examples of areas of research that we have funded recently. And this is by no means a complete list, it's just to give you an example of the breadth and the depth of the research portfolio that we fund.

And some of the areas that we have funded recently are in new drug development and re-

purposed drugs. Targeted therapies and signaling pathways in gene expression. Precision medicine; so looking at the individual patient and how to best treat that individual patient. Also imaging, immunotherapy, which we know is a hot topic of interest, and then stem cells. So there, as I said, are just some examples of some of the research that we fund. We have a very diverse portfolio -- sorry, there's a little delay on this.

We fund research through four different grant opportunities, we call them. And as Ralph said, this is an open call for applications. Which means we post the request for applications and anybody can apply that has a good project and would like to submit one, as long as they fit the eligibility criteria. So as I said, there's [sic] four different grant opportunities that we offer. I'll just go over these very briefly.

The basic Research Fellowships are two-year grants, \$100,000 and these are mentored grants. So that means there's a post-doc working on a project who is under the training of [an] expert in the brain tumor field who can be their mentor.

We also have our Research Collaboration Grants. These are two-year, \$200,000 grants for multi-investigator, multi-institutional brain tumor collaborative research projects. So these are really meant to bring researchers together from different disciplines, different institutions to work together toward a common goal.

We also have our Discovery Grants; these are smaller grants. They're one-year, \$50,000 grants and these are really for high risk, high impact research. It's really meant to be seed-funding for investigators to get some preliminary data so that they can go and get a larger grant. An RO1 or a federal type of grant.

And then finally, last but not least, we have our medical student summer fellowships. And these are, as I said, summer fellowships, they're just for three-month period[s], they're smaller grants - \$3,000 and they are for medical students who want to spend some time in a lab so that they can learn some skills and techniques that may help them to pursue a career in neuro-oncology research.

And through these four grant opportunities that I just talked to you about, we fund research across all brain tumor types. And that includes primary brain tumor as well as secondary brain tumor, as Ralph was talking about, which is brain metastasis. And we also fund all ages of brain tumor; so pediatric to adult. So we have a very - as I said before - a very diverse portfolio of research.

We have invested in over \$32 million dollars in research since we started. So we're very proud of that. We've funded over 700 research projects in the U.S. and globally, because we also fund internationally. And we've funded over 630 different researchers.

We also think it's very important to continue to invest in the next generation of researchers. And so we established the ABTA Alumni Research Network or the AARN, we call it. And we started this network back in 2012 and we bring these researchers together who have been funded by ABTA. And they come to a two and a half day meeting every year, where they get to learn about brain tumor science, but then they also get to talk about grant writing, how to manage a lab, other things that can help them in their careers.

And during these meetings, they also network and form collaborations. And so we've also been tracking some of the collaborations -- if I can get this pointer to work. No, but that's okay.

There are 22 collaborative groups we have counted among the AARN membership. So they have formed these organic collaborations and these have led to joint publications. So as you see, we have 30 joint publications of which we've tracked and we're also tracking joint funding that has come out. So what we're seeing is that these collaborations are leading to more advancements in research as well.

And then I also wanted to mention how we also support research outside of our four grant opportunities. So we also have other research initiatives that we support, and I just have a couple of examples here.

One is the Brain Tumors Funder Collaborative and this a partnership amongst other organizations. Private, philanthropic, as well as advocacy organizations. And we pool our funding to invest in larger studies than we can invest in individually. For example, we have a study, we're funding a study of long-term survivors of GBM, so that we can learn from them.

We also recently awarded \$3 million to four teams of researchers to study immunotherapy approaches in primary brain tumors. And then we also support a low-grade glioma registry, which is a registry that will be used to look at response to treatment and clinical outcomes within this patient population.

Okay. So that's our research program and you can ask me anymore details that you want, I'll be here through the whole meeting. Now I want to transition over to our patient services which I hope a lot of you already know somewhat about, but if not and this is new, I hope you'll learn something as well about our vast patient services that we offer. We have a very robust program that's all free of charge for all patients.

We have our website, as Ralph mentioned. It has a ton of information. We have information on tumor types, diagnosis, symptoms, treatment, side effects and more. You can go in there under the "About Brain Tumors" at the top, that menu and you can find a lot of this information there.

We also have listings of brain tumor treatment centers that you might want to check out and then we also have a listing of brain tumor support groups. And then we have access to our educational brochures which I'll talk about a little bit more, but you can download those from our website. And we also have those as hard copy which you can order from us.

For our educational materials as I just mentioned, we produce 18 educational brochures and they range from anything from individual tumor types to different treatments. As far as chemotherapy, radiation therapy to clinical trials. It's a very vast group of brochures and it's really -- and we even have a caregiver handbook, which you can see here.

If you want any of these you can order them from us free of charge so that you have --if you want something as a hard copy that you can take notes on -- as I said, you can also download these from our website. And we also have some that are in Spanish on our website.

We also have our care line. This is a -- it's a care line as well as emails. And this is where you can call our office -- and the phone number is up here -- and you can talk to trained and caring staff. And they will help you with anything; from providing information to assistance and resources. It's a good opportunity if you want to talk to somebody in person and have a one on one discussion. And this is a very active care line that we have. It goes from 8:30 to 5:00 every day of the week. Except for the weekends.

And then Trial Connect is a free service. It's a clinical trial matching service that we offer, if you want to look through the clinical trials that are available you can go through trial connect and search for them online. You can search for tumor type or treatment. And also, if you want to talk to somebody, a navigator, you can also call the service and they can help to match you to clinical trials when you talk to them. And this is accessible, as I mentioned, online or by phone.

We also have our online support community that we call Connections. And this is a dedicated online community for brain tumor patients and caregivers. We have over 21,000 members, so this is a very popular community, and if you haven't checked it out, I would suggest doing so. Because this is a really great resource online. It's a little different from, if you would go to Facebook for example, because it's private and you can post things anonymously. If you just want to ask a question and you don't want everybody to know what you're posting, it's a good way to be anonymous. It's really forum [sic²] -- it's set up as a forum format. So there's questions posed and then you can have conversations around those topics or questions. And you can even search by topic or tumor type.

We also have our webinars, and these are free, monthly webinars that we hold and they range in a number of topics. From different treatments to symptom management, to diet and nutrition, and we hold these webinars live so you can ask the speaker questions during the webinar. But we also record them and we keep them on our anytime YouTube learning channel. So you can go and visit those at any time that is convenient for you.

We also offer a unique peer to peer mentoring service and this mentoring service connects

²[sic] is used to denote a section where the content was transcribed correctly despite speaking errors.

newly diagnosed brain tumor patients and caregivers with mentors that have a similar diagnosis or have had a similar -- if it's a caregiver, they've had experience with a similar diagnosis. And it provides somebody that you can talk to whose walked in your shoes. Somebody that can offer support. We have over 200 patient/caregiver mentors and 600 mentees are matched. So this is a very popular program. If you're interested in it, please find any of our staff and let us know and we're happy to get you involved in this program.

We also have our regional patient and family meetings and these are similar to our national conference, where we are today, but these are one day educational meetings. And these are also led by medical experts, we bring patients and families together. And we cover topics that include research updates, treatment overviews and side effect management. And these regional meetings, we have six right now around the country, and so if there's one in your neighborhood or if you know of somebody who could go to one and who could benefit from one of our regional meetings, please let them know. You can find out more information on our website.

And then our national conference, which you all know about. We have this every year, here in the Chicago area. This is our largest meeting -- it's a two-day meeting where we bring together not only patients and families but really all of the constituents in the brain tumor community. Health care providers, staff, board members -- we have such a large audience for the national conference.

It includes a number of topics; newly diagnosed, topics around caregivers and survivors and we have obviously, in person attendance by Livestreaming.

As you can see, we offer a lot of patient services. I'm happy to talk to you in detail about

any of those if you want to know more information. But right now, I want to turn it over to Brandon Starkoff who's our Vice Chair of the board of directors and he's going to tell you a bit more about how you can get involved.

[Applause.]

Mr. Starkoff: Thank you, Nicole. That was great. I think it's obvious to many of you in the room and online that the ABTA is full of some really smart people that are helping to network and bring a lot of great, smart people together to help solve obviously a big challenge in our society, and they're here to support all of you. There's a lot of passion and energy and intelligence that's coming together and today I'm going to talk to you a little bit about how to get involved.

As Ralph pointed out earlier, I am an eight-year survivor of this and very passionate about this community. And as a volunteer board member who's gotten involved in a variety of activities, I want to introduce you to a few of those today. And talk about how you can get involved in the ABTA.

So some of you may be aware, some of this may be new. Several events -- fundraising events that we have across the year. And in order to support -- they're used in order to support our research initiatives and to provide top notch patient-caregiver resources. The ABTA relies heavily on our brain tumor community. So that's you and the people online and the people outside of that to help us raise the much-needed funds to support all the efforts that Nicole was referencing.

To begin, the Breakthrough for Brain Tumors 5k Run and Walk takes place in ten cities across the U.S. and is designed for all ages. I take my kids every year, they're nine now. They've been going since they were three. You can register as individuals or start your own team. I

participated in the BT5k -- Chicago BT5k and the Columbus BT5k for years and have always loved seeing the brain tumor community come together to support their loved ones impacted by brain tumor diagnosis.

There's also Team Breakthrough, which is designed for avid runners or cyclers to raise money for the ABTA by competing in long distance races like marathons or half marathons and even other bike races in their community.

Our most popular is our Fundraise Your Way program. Whether you host a wine tasting night, a golf tournament, a birthday party or even a rodeo -- it's been done -- Fundraise Your Way helps you to raise money doing what comes easy for you. Our programs allow you to easily create your own webpage, disseminate through emails and collect donations.

For six years now, my wife and I have hosted what we call Caterers for the Cure, which brings together donors, survivors and other supporters with some great foods, some great music and a silent auction. And through those initiatives over the past six years we've raised \$350,000 to help ABTA (inaudible 00:46:22).

[Applause.]

And I want to point out that that event was not inspired by my own diagnosis, it was actually inspired by a close friend of mine, who passed away a couple years ago. It was really that, and it's really taken off. We appreciate a lot of folks from the ABTA help support that. I just want to give a big thank you back to the ABTA for being involved in that. And certainly all the researchers that have been able to use those funds, we've had some great results from that.

So I also want to talk about the various volunteer opportunities that we have. So each Breakthrough for Brain Tumor 5k Run/Walk has a committee of local volunteers that help promote and plan the event locally. Committee members work with ABTA to make their organizations signature fundraising event a huge success. Each volunteer -- an event volunteer support[s] the ABTA hosted event, including the BT5k Run/Walk, regional locations and family meetings and the national conference that you're at today.

Volunteers with specific skills are often needed to help support ABTA with special projects. There may be opportunities for graphic designers, photographers, videographers, social media gurus and writers to use their skills and talents. We know there's a lot of you out there. We'd love to have you join us and support our cause, so we can get our message out there more quickly and extend our reach.

In order to stay up to date with everything ABTA is doing, make sure you're signing up for Mind Matters, our monthly newsletter. Join our social channels; that's really important for us. You can get exposure to a lot of the new efforts that are underway; the research, the funds that we're raising, the events we have. There's a lot of great information that comes through those social feeds. So if you have not signed up, I would certainly encourage you to. Encourage your friends and family to do the same and certainly be part of our community in a social space. It's real news. It's real information to be clear. And it's really important and concise. That's right.

So in summary, you know, the American Brain Tumor Association is here to support every step of the way. They were there every step of my situation and many other people that I bring into the organization. We're here to help you along your diagnosis and are seizing every

opportunity to advance the science so that one day, we can beat this challenge of this disease.

I want to thank all of you for coming in today, both here in the room and for those online. Thank you again and I look forward to a really solid couple of days. Thank you.

[Applause.]

Ms. Spawn: Thank you so much. I think that was a great presentation and we all learned a lot about ABTA's resources. As Nicole said, if you are interested in any of those please come out and reach out to any of the staff members and we can tell you more about what we do. You can also stop by our booth outside and learn a bit more or sign up for any of our services.

Next, I would like to take this opportunity to invite Dr. Dunbar back on stage. She will be introducing our next speaker. Thank you.