

FOR IMMEDIATE RELEASE

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Ocean City Serves as Home to Inaugural East Coast Cranio Survivors Picnic

Ocean City, MD — Survivors of craniopharyngioma, a rare and complex benign brain tumor, and their families joined together for the inaugural East Coast Cranio Survivors Picnic at Northside Park in Ocean City on Saturday. The group also included spouses, parents, siblings and grandparents, who provide support to each other on Facebook as part of a group page specific to the tumor. The picnic was organized in part by the Raymond A. Wood Foundation (RAWF), whose mission is to provide quality-of-life support for survivors of childhood brain tumors and their families.

Craniopharyngioma is a mass that grows from a set of cells near the pituitary gland and occupies the sellar and suprasellar regions in the brain. It can cause damage to the pituitary gland, hypothalamus and other nearby parts of the brain. The tumor and treatment can leave patients with long-term comorbidities or side effects, including loss of pituitary function, uncontrollable weight gain, growth deficiencies, diabetes insipidus or the inability to control fluid balance in the body, adrenal insufficiency, social and behavioral issues, memory issues and cognitive deficits.

Most of the survivors in attendance were diagnosed as children. Survivors ranged in ages from 6 to 70 and traveled from as far as Florida, Georgia and New Hampshire.

“This is an amazing opportunity to connect in person, share experiences and exchange information,” said Amy Wood, director of RAWF and mother of Alex, survivor and Ocean City Elementary School kindergartner. “The conditions from this tumor are so tricky and often misunderstood in the medical community. Sharing discoveries of what works in day-to-day management is so beneficial.”

There is a West Coast meeting of survivors that has been a successful annual event in Redondo Beach, California, for many years, but several members pitched the idea of an East Coast version late last year and decided on Ocean City as a perfect central location and an attractive destination. Attendees enjoyed a beautiful day at the park, a barbecue lunch and some rounds of cornhole.

“I think we all had a great time today getting to meet each other in person,” said Frederick Kunitz, survivor and event organizer. “There is nothing like being around other people who understand what its like to deal with this tumor.”

RAWF, a 501(c)(3) charitable organization founded early this year, provided food, secured the venue and printed souvenir T-shirts for the survivors.

“Childhood brain tumors have a 66% survival rate, but many of the treatments are so aggressive on the developing brain and these kids face a lifetime of challenges,” said Wood. “With diagnoses on the rise, we felt we needed to find a way to help kids and families dealing with the ongoing effects.”

To find out more about the Raymond A. Wood Foundation or make a donation, visit rawoodfoundation.org.

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Photo Caption

18 survivors of craniopharyngioma, met up in Northside Park for a picnic Saturday.

Pictured from left to right:

First row: Landry Stamm (DE) and Alex Wood (MD)

Second row: Chris Harsch (PA), Emily Powell (MD), Sydni Gajewski (PA)

Back row: Elise Rosati (NJ), Jake Borsh (NH), Isaac Feil (NJ), Frederick Kunitz (GA), A.J. Selko (NJ), Jonas, Bilenas (PA), Jacob Reid (WV), Brittany Rinker (WV)

Not pictured but in attendance: Mikey O'Connell (VA), Sriyani Roberts (VA) and Christopher Ramirez (FL)

Photo credit: Emily Powell Photography