Tranent couple want to raise awareness about teenage cancer

A Tranent couple, who have just returned to Scotland after spending two months in America getting medical treatment for their daughter, are keen to raise awareness of childhood cancer, and urge all parents to be on the lookout for warning signs. They also want to express their gratitude to everyone who supported them during their daughter’s illness and who donated to their fund.

In January the lives of the Yates family were turned upside down when 12 year-old daughter, Niamh, was diagnosed with an undifferentiated sarcoma on the base of her spine. All childhood cancers are rare, but this was a particularly rare form of tumour. Treatment initially began with a seven hour emergency spinal operation to prevent what was becoming serious nerve damage to the lower part of her body.

Niamh gets on-going physiotherapy to help overcome the difficulties she has developed during six cycles of chemotherapy at Edinburgh’s Royal Hospital for Sick Children. On 13 July this year, the family travelled to the University of Florida Proton Therapy Institute in Jacksonville for a seven week course of proton beam radiotherapy.

A daily commute and treatment averaged three hours each day, and in addition to the excellent treatment provided at the institute, part of the recuperation process involved the Florida sunshine where Niamh quickly lost the ‘chemo pallor’ and also benefitted from daily swims in the nearby pool with physiotherapist, Tom, and younger brother Conor.

With plenty of spare time, the family quite rightly made the most of their stay in Florida, and managed to take in some WWE wrestling involving some big names including John Cena, CM Punk and Daniel Bryan, as well as visiting the famous Cocoa Beach and the Kennedy Space Centre, where they tried a rocket flight simulator, viewed the Imax Hubble Telescope experience and the Cape Canaveral Launch pads.

At Hollywood Studios in Orlando, they saw the Indiana Jones Show and tried the Star Wars ride, while at SeaWorld, Niamh enjoyed all the shows especially Shamu the killer whale, and Pets Ahoy where pets adopted from animal rescue shelters feature star in it.

Niamh was also able to swim with the dolphins at Marineland which is reputedly the oldest dolphin park in the world and also has the world’s oldest dolphin in captivity there, aged 59.

Despite their adventures, no-one in the family ever lost sight of the real reason for being in America as mum Julie explained:- “Yes, we’re in Florida, it’s a wonderful place and perfect for Niamh’s recuperation, but we are here on our own, no family apart from each other, no friends I can see for a wee chat – we are just the four of us dealing with it all together. It’s bloody hard work actually and anyone who thinks we are having a “holiday” out here can think again. It’s not a holiday. Yes it’s hot, yes we’ve been making the most of our time here when we can (thanks to the wonderful generosity of family and friends) but it feels far from a holiday to us. The stark reality is that we are here for a reason, to get our lovely Niamh well again, back to her normal self, cancer free, back to school, back with her friends where she belongs.”

Before coming home, the family managed to take in the sights of Washington DC where they saw the White House, the

Washington Monument, the WW2 Memorial, Lincoln Memorial, Capitol Hill, Korean War Memorial and Vietnam War Memorial, as well as three of the Smithsonians (Natural History, American Indian and Air and Space).

Finally, after 36 sessions of proton lasting seven weeks, Niamh was rewarded with a party at the institute, where gifts and a cake were the order of the day.

Julie continued:- “It’s been hard work with the best part of three hours a day taken up with the appointments, not to mention trips to the Oncology team and also her physio. It’s been gruelling and tiring for her (and us) but she has done amazingly well. Her doctor here said she has tolerated the treatment very well (and she’s had a lot of radiation) and they are very, very pleased with how it’s gone. We are just pleased it’s all over so we can move on with our lives. Hopefully she won’t require any more treatment whatsoever apart from regular scans and check-ups. We will not get an MRI scan for a while due to inflammation at the tumour site, so until then, we concentrate on getting Niamh fit and ready to return to school.”

The final stop before returning home was the Big Apple where the family stayed on the 46th floor of the Crowne Plaza Hotel over the Hershey’s shop in Times Square, and took a helicopter tour of the city which included a close up of the Statue of Liberty.

They also did the obligatory ‘tourist’ type things in New York, and went for meals at The Hard Rock Cafe and Bubba Gump’s Shrimp Company. The fact that Niamh was able to do it all without using her wheelchair was particularly encouraging.

A visit to Manhattan for childrenwould not be complete without a trip to ‘ToysRus’ in Times Square which ended with the unusual sight of four policemen arresting a man dressed as Elmo outside the building.

Both Julie and Paul are desperate to raise awareness about children’s cancer, and urge all parents to look out for the signs as early diagnosis is vital.

Julie said:- “September is Childhood Cancer awareness month (in the USA). Early diagnosis is the key, but lack of funding and research into children’s cancers means that GPs often don’t recognise the symptoms and therefore there’s always a delay in being diagnosed. This delay can be the difference between life and death. So you, as parents, must educate yourselves on the signs of cancer in children and trust your gut. It’s not as rare as you might think. Check out this website for more information Bechildcanceraware.org.

“I get so angry sometimes at the situation – this ***** tumour and what it’s done to her. Watching her limp around in tears, clinging onto Paul for support trying to “walk it out” breaks my heart. It took a good hour before it eased off for her. How dare cancer do this to my child! It has robbed her of almost a year of her life. It has affected our family in ways I cannot even begin to explain. There are still things that occur on a daily basis due to the tumour even 7 months after her operation that I can’t begin to go into here. It’s an ongoing battle for her and us which will continue for some time to come. All she wants is to be normal, a normal teenager but she can’t be. Not yet anyway. The cancer treatment has ravaged her body, made her sick, had her hooked up to machines for days on end, put poison into her body which may have caused long term side effects, caused catastrophic damage to her nerves and shattered her confidence. We still have a long road ahead of us, but we’re getting there.

“After that it’s hopefully back to normality with no further treatment as soon as possible – Paul is looking forward to returning to work and Niamh to school.

“Thank you so much to all who donated to our fund and who continue to support us – we really really couldn’t have done this without you and send gratitude from the bottom of our hearts. we can’t thank you enough and hope to continue fundraising to help other families affected by paediatric cancer on our return!”

Anyone wishing to contribute can do so at http://www.gofundme.com/allaboutniamh?utm_medium=wdgt