

By Gerard Condon

IKE MANY 17 year olds, Joanne O'Riordan likes to collect wristbands. She has one for the boy band *One Direction*, and another is a souvenir from a recent school trip to Paris. Others read: *Take Care in the Sun* and *Believe in Yourself*. But Joanne's wristbands hang from a motorized chair. She was born with Total Amelia Syndrome, which means she is without arms and legs. It's an extremely rare condition, shared with just seven others around the world.

Joanne is from Millstreet, a town in north County Cork with a population of approximately 1,500. Against all the odds, local entrepreneur Noel C. Duggan succeeded in staging the Eurovision Song Contest here in 1993.

That same fighting spirit epitomizes the town's most notable person today.

# **Amazing dexterity**

Joanne is the youngest daughter of Joe and Anne, after whom she is named. Her father works in a Duggan steelyard. Her mother is a homemaker who raised Joanne together with her sister and three brothers. "There were times when I didn't know how we would be able to cope," Anne tells me. "As a baby even simple things like a buzzing insect or the sight of a butterfly would upset Joanne terribly because she couldn't swat them away. She was completely helpless."

Education and technology have given Joanne a measure of independence. She learned to write by picking out the letters on a keyboard using a pen held in her mouth. Helpful teachers scanned her textbooks onto CDs and later memory sticks. Now Joanne uses wireless technology to manage information. She can type at a rate of 36 words per minute.

Joanne was first fitted for a motorized chair at the age of two. "We have kept the original chair in the garage," Anne tells me, "as it was such an important part of Joanne's life-story." Controlled by a joystick, Joanne's current 'car', as she calls it, has a top speed of 5km and weighs a hefty 76kg. "It takes quite a few lads to lift it whenever we run into steps," Joanne tells me. Joanne can perform everyday tasks such as brushing her teeth and eating with the use of her upper and bottom lip, chin, nose and



partial left arm. She can use computer devices, such as her iPhone, with an amazing dexterity.

#### Build me a robot

In April 2012 Joanne travelled to New York to address a United Nations conference on *Girls in Technology*. The meeting focused on the benefits of technology for people with disabilities. "Technology is the limb I never had," she told the two hundred delegates. She concluded the address with the challenge to "build me a robot... this robot would become my hands and

Joanne with her mother Anne; "There were times," Anne says, "when I didn't know how we would be able to cope" legs... I can't rely on my parents, my brothers, sister and others all my life. Can I? Certainly not, and I don't want to! I want to live an independent life just like you." Several world-class agencies have since been in touch, including a robotics laboratory at the Massachusetts Institute of Technology. The robot she envisages would respond to voice commands and help with simple tasks like picking up things that fall. "Maybe the new robot could also swat nasty bugs away?" I suggest. "That would be handy too," Joanne agrees.

### **Public outcry**

Ireland's culture of respect for human dignity has been a reservoir of support for the O'Riordans. The family moved from nearby Drumtarriff to a specially adapted house when Joanne was 3 years old. She was one of the first children with such a disability to be given the right to mainstream Primary and Post-Primary education in her locality. This is made possible by the presence of a dedicated Special Needs Assistant in the classroom.

However that level of care is being threatened by the Government's

austerity program. When Enda Kenny, the leader of the Fine Gael party, visited Millstreet in the general election campaign of 2011, Joanne took the morning off school to meet the candidate. He promised her, on camera, that there would be no cuts to disability payments for under-18s. Months later, Taoiseach (Prime Minister) Kenny sanctioned precisely these cuts. Joanne wrote him an open letter, a reminder of his broken promise. The ensuing public outcry quickly forced the Government to reverse the budget measure.

## Young Person of the Year

Joanne has no fear of being in the public eye. She has made a number of appearances on *The Late Late Show*, the most popular TV program in Ireland and the longest running chat show in the world. The *Irish Times* described her as "one of the guests on the show in recent years who has made the most impact on viewers." In an interview she told the newspaper, "People used to say: she's the one with no arms or legs. They're nicer now." (June 1, 2012).

In 2012 Joanne was named Young





Person of the Year at the People of the Year Awards organized by the Rehab Group. Her brother Steven, with the support of the Irish Film Board, is making a documentary about her life with the title, *No Limbs, No Limits.* The premier will be screened at Cork Opera House next October. "It will be a reality-TV-style documentary," Joanne says, "our own version of *Meet the Kardashians.*"

Joanne is regularly invited to talk about her life in parish churches around the country and, at other times, to meet people who have acquired a disability through an accident. "They can be very depressed by their disabilities. I try to inspire them not to be afraid, to cheer up, and not be negative." She is surprised at the number of young people interested in what she has to say. "Teenagers can be ridiculously cruel or ridiculously kind," Joanne declares. Once when a boy asked her why God made her the way she is, her reply was that "we are each special in different ways... and God made me that extra bit special."

#### **Devout family**

Joanne has been to Lourdes on seven occasions, mostly with the annual pilgrimage of the Diocese of Kerry; Millstreet is in that part of County Cork which forms part of Kerry Diocese. For Confirmation she took the name Bernadette, after the Lourdes visionary. The recently retired Bishop of Kerry, William Murphy, has become a family friend from their meetings at Lourdes and elsewhere. Anne and Joanne receive an invitation to visit his house in Killarney each Christmas. Last year she presented a Cork Gaelic footballer's jersey to the Bishop. Not to be outdone, Bishop Murphy gave Joanne a teddy bear kitted out in the Kerry colors.

Like any teenager, Joanne questions her faith and challenges the traditionalism of the Church. She used to think of God as a "big lad with a beard, dressed in a flowing white robe. Then recently our school chaplain showed a picture of God as a colored man and that made me think, 'Why can't God be colored?" She finds the public demonstrations of faith by Irish Olympic champion Katie Taylor and Barcelona FC star Federació Caça to be inspiring: "They remember to thank God for their achievements." She prays before exams and for deceased relatives and friends, and, "oh yeah, that Cork will win the All-Ireland!" The family celebrates Sunday morning Mass at Millstreet parish church, where there is "a really cool priest." Joanne and Anne agree that this is an important time-out from their busy lives, an opportunity "to day-dream knowing that God is around you."

## **Budding journalist**

Joanne's favorite school subjects are History, English and Agricultural Science. Next year she will sit the Leaving Certificate, the gateway to Third Level education in Ireland. And then? She is interested in becoming a journalist and/or a TV presenter. She already writes a weekly opinion column for The Irish Examiner titled The Way I See It. "I try to write about topics that people don't normally think about," Joanne tells me. She is passionate about animal welfare, especially pets that have been abandoned. Her interest in animals is evident from the three noisy Shih Tzu dogs playing in the garden and a pet turtle that she affectionately calls "Enda Kenny."

Joanne is a remarkably articulate, witty and idealistic young woman. She has a level of confidence that most 17 year olds only dream about. Her family, community and faith have helped Joanne develop her potential. Now she is inspiring many to do the same.