Ann Maxwell has always aimed high. So when she discovered her son Muir had a rare form of epilepsy, she made it her goal to help other families affected by the condition. Her energy and determination made her the unanimous choice of the judges to win 2008’s Clarins Most Dynamisante Woman of the Year, and the £30,000 award which goes with it – an even more remarkable story considering the life-threatening illness Ann is facing herself.

Interview: Josephine Fairley
Photograph: Amit Lennon

Ann Maxwell had headed one particular teacher’s comment in a school report, it’s doubtful that she would have headed the VIP guest list at No 11 Downing Street for the presentation of the 2008 Clarins Most Dynamisante Woman of the Year award last week. ‘If Ann doesn’t lower her sights, it may inhibit her achievements in life,’ her report read. Happily, for many thousands of children – including her own son Muir – Ann, 45, is not one to lower those sights. Why rally your friends round for a modest fundraising cake sale when you can organise a dazzling charity ball that brings in £1.1m – as last year’s Muir Maxwell Trust Masked Opera Ball did? Why settle for boxes of chocolates and foot spas for your raffle when you can rustle up a £25,000 diamond solitaire and a bespoke Alfa Romeo Brera for your prize draw? And, most importantly, why be content with providing 700 epilepsy alarms, offering peace of mind to sleep-deprived parents, when you can devote much of your waking life to working towards a cure for childhood epilepsy, which afflicts 70,000 children in the UK alone?

What really shaped Ann’s destiny wasn’t a teacher’s barb, but the birth of Muir, now 11 (Ann has two other sons, 14-year-old Connor and nine-year-old Rory). When Muir was four months old, he suffered a seizure one night while sleeping in his parents’ bed at their home in Edinburgh. ‘With a tiny baby, seizures are quite subtle. But I knew something was wrong,’ says Ann. Whisking her son to the A&E department, she was reassured to be told it was probably the side-effects of a fever (Muir had been given some vaccinations earlier in the day).

‘But a month later, Muir was miserable and unwell. My maternal instinct told me something really was wrong.’ En route to hospital, he had another seizure – though this, too, had passed by the time she arrived, hysterical, on the hospital’s doorstep. It was several months before doctors put Muir on anti-epilepsy medication, during which time he’d suffered one seizure so severe that his parents almost lost him. ‘It’s called status epilepticus,’ says Ann – basically, a fit that doesn’t stop (in this terrifying case, for more than two hours). Cumulatively, these seizures affected Muir’s brain and, eventually, he was diagnosed with a rare genetic form of epilepsy called Dravet Syndrome.

Muir will never be able to hold a pen properly or to read. His speech is affected and, as his motor skills are also affected, he can’t learn to sign either. By the time he’s a teenager, Muir may be in a wheelchair. But he is clearly adored by everyone who knows him (who have no problems working out what he is trying to communicate). ‘Muir is one of the happiest children I know. Hugely affectionate. Totally beautiful, with a wonderful demeanour. The inspiration to all of us,’ says Ann.

Desperate for information about childhood epilepsy, Ann found a local charity which ran a special playgroup that she was told Muir could join. The day before his first visit, Ann was told the group had been disbanded as there wasn’t enough in the kitty to pay for the group leader. So when Ann got a call from a fellow mother of an epileptic child, inviting her to a fundraising fashion show, she went along.

Not long after, Ann bought three tables for friends at a ball for this local epilepsy charity, which raised £50,000. But Ann had her own vision – and her sights, as that teacher identified, were set high. When the ball’s organiser declared she wasn’t up for a repeat performance, Ann stepped in. ‘I pledged to give the charity £50,000 out of what we raised,'
with the rest going to establish the Muir Maxwell Trust."

Whereupon, Ann brazenly announced her intention to stage ‘the most glamorous event that Edinburgh had ever seen’. Ticket prices were an unprecedented £150 a head. Prize-draw tickets were a staggering £100, but it paid off, raising £40,000 from the raffle alone. The first ball netted over £200,000, and since then the annual Muir Maxwell Trust extravaganza has become one of the most successful events in the charity calendar, raising more than £3.5m since it was launched five years ago. High-profile supporters include Christopher Biggins – who chose the MMT to benefit from £25,000 he scooped on a celebrity episode of Who Wants to be a Millionaire – Natasha Kaplinsky, Joan Collins and Lorraine Chase.

Ann’s secret is that, cleverly, she has tapped into the generosity of affluent friends and contacts in the financial world (she’s a former financial planner and husband Jonny works in private equity). ‘They saw what we went through with Muir, and have been incredibly supportive,’ she says. ‘Often, they were on the receiving end of e-mails from me, sent at 1am, telling them that I just couldn’t cope any more – so they understand how devastating this condition can be for families.’

What eventually offered Ann and Jonny peace of mind while caring for Muir was a simple epilepsy alarm; placed beneath the sheets on which a child sleeps, it is sensitive to movement and alerts parents to a seizure. (Night-time seizures can be extremely dangerous and there is a risk of Sudden Unexpected Death in Epilepsy – Sudep – which can be avoided if the child is placed in the correct position to breathe.)

‘Sleep deprivation is a recognised form of torture,’ Ann says, ‘but it’s something parents of epileptic children can endure for years. Parents sleep with the child in their bed, or in their child’s room, or simply take turns to get up in the night every half an hour to check on them.’ The monitor Ann and Jonny bought was a type used in hospitals,
Eighty per cent of my tumour was removed in two operations. I faced death twice. Because of that, now every day is precious, a bonus.

The monitor has allowed us to put some normality back in our lives, giving us the confidence to allow our daughter to sleep in her own room – and giving us a rest. Or, ‘The monitor has been brilliant. As a parent, I feel much better and I am able to sleep.’

But no way was Ann going to stop there. So another part of the Trust’s work has been funding an £80,000 DNA sequencer machine, which is leased to the NHS, to help with early identification of genetic epilepsy. It has also funded two ‘video telemetry’ units to assist with diagnosis, helping doctors to identify the drugs or other treatments which may prove most effective in a specific child’s case, eliminating a lot of trial and error.

‘There are many different forms of childhood epilepsy,’ Ann says. ‘They each respond differently to different drugs or diets.’ So the Muir Maxwell Trust also sponsors two ketogenic diet clinics: a little like the Atkins diet, with a focus on protein, a ketogenic diet can help to control symptoms in some children. But that’s not all. Oh, no. Eventually, as Ann proclaims, her goal is nothing less than ‘to find a cure for paediatric epilepsy’.

And her son’s epilepsy isn’t the only challenge that has faced Ann Maxwell on her path to becoming the Clarins Most Dynamisante Woman of the Year. Because she herself is suffering from an incurable – albeit currently slow-growing – cancerous brain tumour, diagnosed in 2005. ‘One side of my face went numb,’ she recalls. ‘I mentioned it to my dentist, who didn’t dismiss it but said I might have something pressing on a facial nerve.’

With her annual ball looming, Ann scheduled an appointment with her doctor for the Monday after the party was over. Subsequently booked in for an MRI scan, Ann felt like a fraud: ‘I couldn’t believe they said I might have something pressing on a facial nerve.’

But she was so convinced the numbness was down to a virus that she squeezed the appointment to hear her diagnosis between two other important commitments – but instead, found herself being ushered to another hospital department to see a consultant neurologist. ‘Nobody mentioned the word “tumour” to me. So I texted my husband – who was in California – to say they’d found a growth, and promptly turned my phone off.’ Frantic, Jonny Maxwell jumped on a plane to be with his wife, who later underwent two operations to ‘untangle’ the tumour, which had macraméd itself around the cranial nerve.

‘Eighty per cent of the tumour was removed in two operations, during one of which they removed my inner ear – so I am now deaf in that ear,’ says Ann, in the most extraordinarily matter-of-fact way. ‘I faced death twice, because the operations were so complicated. I put my affairs in order, talked to my children – because I had to face the possibility that I might not see them grow up. But because of that, now every day is precious, a bonus. I don’t have a fear of death – and I certainly have an appreciation of life that I never had before.’

Nevertheless, as the lynchpin of the trust founded in her son’s name, and with a question mark over her health, Ann is fully aware of the need to secure the charity’s future. And so the generous £30,000 Clarins award money will underwrite two years’ salary for a full-time fundraiser, ‘with the aim of turning that into at least £160,000 for the purchase of epilepsy alarms,’ says Ann.

Friends insist that Ann Maxwell is a one-off, irreplaceable – yet Ann is convinced that ‘there’s somebody with as much dynamism who can inject his or her own energy into this project, and drive it forward’. As much dynamism as this year’s Clarins Most Dynamisante Woman of the Year? It’s a tough call. But as her teachers, friends, family and colleagues know: when Ann Maxwell sets her sights on a goal, who’d dare to doubt her?

To make a donation or to find out more, log on to muirmaxwelltrust.com or call 0131 273 5255

OUR OTHER DYNAMIC CLARINS FINALISTS

LOUISE MASSAMBA’S Merseyside Refugee & Asylum Seekers Pre and Post Natal Support Group (MRANG) cares for women, children and pregnant minors, championing their cause with social services, the medical community and immigration authorities – and providing a day centre in a local church hall.

SUE HAYWARD, who founded Working for the Children of Watamu after a holiday to Kenya in 2003, has built three schools for 700 children, with a library of 15,000 books (shipped from the UK), and a computer room. Next on Sue’s agenda: Happy House, for children orphaned by malaria, Aids and other diseases.

KAREN HILLIYER joined the Erb’s Palsy Group in 1991 after her son was born with the condition. The condition is caused at birth and results in a lack of movement, growth and feeling in one arm. Through the education of midwives, the group has helped to reduce the incidence of Erb’s Palsy dramatically.

AMY HATHAWAY decided to devote her life to working with children in Africa after watching the Ethiopian famine unfold on the TV news as a child. Today, 28-year-old Amy runs Forever Angels Baby Home in Tanzania, an orphanage for 40 infants (many of whose families have died of Aids).

HEATHER LAST, an occupational therapist, founded the Pace Centre in Aylesbury in 1990 to offer life-changing conductive education to children aged from three months to 11 years with physical disabilities, such as cerebral palsy.

JO BAKER-WATSON set up Megan Baker House which offers free conductive education to children, as well as counselling and support to parents and carers. It was set up in memory of her daughter after Jo and her husband David saw how the technique helped Megan during her short but precious life.