DID YOUR CHARITY WIN

This month, the Mail and RBS are giving £1m to a host of children's charities. Today, we announce the winners – as voted by you, the readers ...

BEFORE Christmas, The Royal Bank Of Scotland and the Daily Mail teamed up to launch a competition to give away £1million to children's charities across the country.

The Mail invited you, its inspirational readers, to nominate the registered children's charities you felt were most deserving of the money.

The 90 charities listed on the opposite page will receive £10,000 each, and one other, voted the winner by readers, will receive £100,000.

Today, we can reveal that the top prize goes to Unique, a charity providing support to the parents of children with rare chromosome disorders.

This means that a tiny part of one of the 23 pairs of chromosomes in each of the children's DNA make-up is missing or has developed too much. This can lead to all manner of mental and physical disabilities. One in 200 babies is affected by one of these disorders, but nearly every child's condition is unique. There are thought to be around 300,000 sufferers in Britain. However, Unique is the only support service for them. Founded in 1984 by a group of parents and run by a skeleton staff of four, it has helped hundreds of families.

Beverly Searle, chief executive of Unique, says: 'As a small charity, we are absolutely ecstatic to have won this award, especially since the other finalists are mostly much larger children's charities which are already household names. We would really like to thank everyone who voted for us — we are overwhelmed by their wonderful support.

'The £100,000 will help us continue our work and also to kick-start our Beating The Isolation programme. Through this we want to reach out to the "hidden" families with children affected by rare chromosome disorders.

'These are families who find themselves challenged by caring for a child with a rare chromosome disorder and who feel as if they are on their own. Winning the award also allows us to raise awareness of rare chromosome disorders and the extraordinary challenges they bring.'

The best way to showcase the work of the charity is through the testimony of parents whose children have been helped. Here, two mothers tell their uplifting stories.

MAX SAINTY is five and suffers from a disorder which affects his mental development and has given him deformed fingers and toes and spinal curvature. His parents, Sophie, 38, and Henry, 41, a solicitor, live with Max and his little sister Martha, three, in West London. Sophie says:

LAST summer, I watched my two children running towards me hand in hand, both of their faces full of laughter, and I grinned with delight.

It hasn't been an easy five years because of Max's condition, but it is moments like this that convince me that it's worth the fight and that we must do everything we can for Max. Looking back, it's difficult to believe how far he's come.

The night Max was born was the worst of my life. Within minutes, the doctors told us he had unusual features, such as the shape of his eyes, nose and chin. They said he would probably be disabled, but they didn't know to what extent.

They did some genetic tests, saying that they thought it was a genetic problem like Down's syndrome, but they couldn't say any more until the tests came back. A few days later, they landed us with the bombshell that one of Max's chromosomes was duplicated. They didn't know what that meant for his future, but they gave us a list of what he might not be able to do, such as walk, talk or feed himself, and when we pushed them for a more definite diagnosis, they said they didn't know.

Not knowing how it would affect him was even harder than cold facts; it felt as if my whole world had collapsed.

Would he be wheelchair-bound? Would we have to feed him through a tube? Would he live to adulthood? I fired these questions at the doctors, but nobody knew anything.

Determined to find out all we could about chromosome disorders, we found the Unique charity by searching the internet. On their website, they had a host of facts and figures for parents of children like Max. It was a magical discovery for us.

We came across other child sufferers who were happy and smiling, and although they progressed slower than most, they were still enjoying a quality of life I had written off for Max when he was born.

Unique also put us in touch with a member whose child had almost exactly the same chromosome disorder as Max.

Although Unique is a British-based charity, they have members from across the world and this child's parents were in Singapore. The little girl was French and two years older than Max.

It gave us enormous encouragement when her mother told us her daughter could understand English and French and even went to a mainstream nursery.

Without Unique, we would never have had such high hopes for Max. When you have a child who is ill, any encouragement can go a long way to seeing you through the toughest times.

We had a long, painful series of hospital visits to track his progress. Every time we went, we saw babies of Max's age learning to crawl and developing co-ordination skills, while Max wasn't developing at all. This is part of his chromosome disorder, so we are thrilled every time he reaches a new milestone.

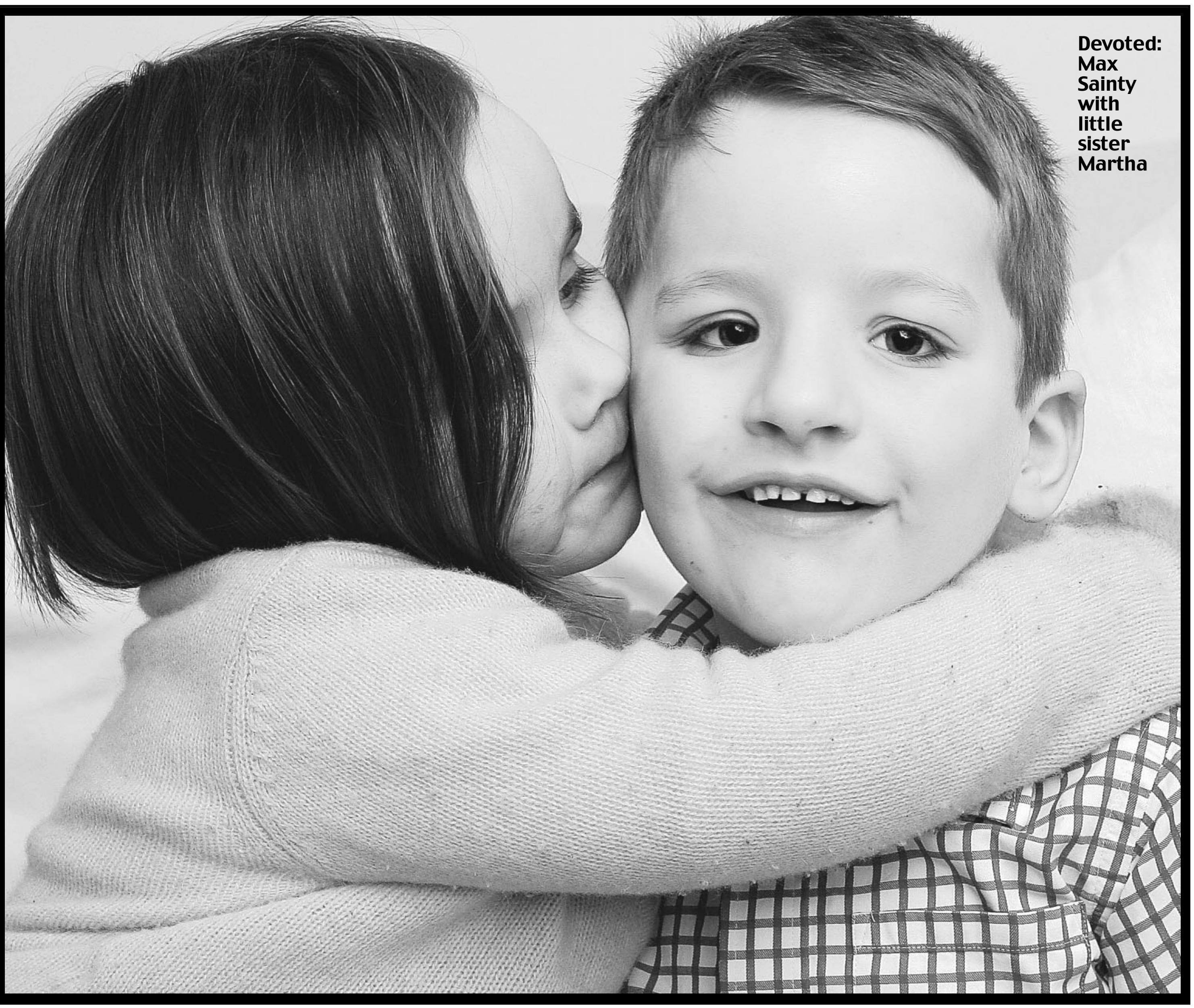
We cracked open the champagne when he first crawled at the age of two. And in a holiday cottage in Herefordshire, at the age of four, he give us one of our happiest moments when he walked by himself for the first time.

Even more special was when his character came through. When he was only two, he became very fashion conscious. I let him pick out his own outfits in shops and to my surprise he chose smart vest-style woollen jumpers and shirts to match.

Now his favourite shop is Gap. In fact, 'Gap' and 'more' are the only words he can say.

Although he can hardly talk, we know from a leaflet put together by Unique that he will eventually pick up speech and we are also

OUR £1m GIVEAWAY?



Devoted: Max Sainty with little sister Martha

Picture: JENNY GOODALL

teaching him sign language just in case.

He went to a normal nursery, although he needed a special teacher to supervise him, and he has just started mainstream school with a similar support teacher.

He might not stay there when he reaches his teens, but at least he is being integrated socially and making friends.

HOPEFULLY, one day he will be an independent adult. I'm not sure if he will have a relationship or get married, but we hope he will be able to get the bus by himself and make some lifelong friends.

When I was pregnant with Martha, it was an enormous concern she, too, might be disabled, but I had an amniocentesis test. Thankfully, she had normal chromosomes.

Now she is three, she is fabulous with Max.

When I look back, it is such a shame that the doctors at our hospital didn't know about Unique or chromosome disorders such as Max's.

It would have helped us immensely in the early days to understand his condition and what the future held for him.

I've been told now hospitals are referring people to Unique much more quickly, which makes it all the more important that the Mail's readers have chosen to support Unique with this £100,000 prize. It is a lifeline in the dark and gloomy world you are plunged into when your child is diagnosed with a chromosome disorder.

It is more than just a website; they organise conferences for families and when a new family comes to them, they put them in touch with other parents of rare chromosome disorder children who live locally.

Also, through Unique, I found out about the home-learning service run by our local council, where representatives teach you how to play with your children.

And Unique doesn't just help parents. Care workers, teachers, social workers, midwives, health visitors, obstetricians, paediatricians and geneticists all turn to Unique for information from its priceless database.

Henry and I will be forever indebted to the charity because they offer a service that is so invaluable.

I can only hope people continue to donate to the charity so they can help more children like Max.

SARAH TREVITT, 34, has one child Maisie, four, who was born with too much chromosome 4p and not enough of chromosome 11q. Sarah and her husband Pete, 41, a technical support consultant, live in Weston-Super-Mare. Sarah says:

'THE hardest thing about when Maisie was born was the sea of blank faces at the hospital when we asked about her future. When she was ten days old we found out about her rare chromosome disorder. It was so rare nobody could give us any answers and the feeling of isolation was overwhelming.

She had severe learning difficulties and would not be able to walk or talk, but we wanted to be positive about her future.

The first time we got that glimmer was when we called Unique. When Pete finally plucked up the courage to call I was amazed to see him smiling as he discussed Maisie's future with an adviser.

Suddenly, it felt as though we were not alone. Through Unique's website we learned more about Maisie's condition.

We discovered that children with conditions similar to Maisie had blood-clotting disorders. This could be fatal if she needed surgery. That meant we were fore-warned, and now we can alert the doctors if she needs an operation. In effect, Unique saved Maisie's life.

Hope for the future: Maisie Trevitt

We have made great friends through the charity and we have gained confidence that with the right medical help and knowledge we can get over any hurdle.

Maisie goes to a special needs school. Given enough time we are confident she will walk. She'll always need care but we don't know yet how much.

Maisie's condition is inherited from her father. It hasn't affected him at all but the odds are against us conceiving a healthy child. However, for now we are positive about the future for our little family.

■ *TO donate to Unique, visit www.rarechromo.org*

INTERVIEWS: ANNA SEAMAN

THE 90 CHARITIES THAT WILL EACH RECEIVE £10,000

Aberlour Child Care Trust
Acorns Children's Hospice
Anthony Nolan Trust
Barnardos
Birmingham Children's Hospital
Bluebell Wood Childen's Hospice
Bobath Children's Therapy Centre Wales
Brian House Children's Hospice
Butterwick Children's Hospice
Chas — Children's Hospice Association Scotland
Chase Hospice Care for Children Ltd
Cherubs UK
Chestnut Tree House
ChildLine
Children North East
Children 1st
Children 1st — Child Contact Centre
Children With Leukaemia
Children's Hospice South West
The Children's Trust
Claire House Children's Hospice
CLIC Sargent
Cosmic Charity
Cystic Fibrosis Trust
Daisy's Dream
Delta
Demelza House Children's Hospice
Derian House Children's Hospice
Donna Louise Trust
Down's Syndrome Scotland — Edinburgh and Lothian Branch
East Anglia Children's Hospice
Echo
Ellenor Shining Lights Children's Hospice
Evelina Children's Heart Organisation
Francis House Children's Hospice
Friends of Ashbeach
Grace House North East
Great Ormond Street Children's Charity
Grocott Centre
Helen & Douglas House
Hollybank Trust
Hope House / Ty Gobaith Cymru
James Hopkins Trust
Julia's House
Keech Cottage Children's Hospice
Kids Company
Kind
Little Havens Children's Hospice
Little Princess Trust
Make A Wish Foundation
Martin House Children's Hospice
Menphys SOS
Moorfields Eye Hospital — Children's Eye Clinic
N C H Children's Charity
Naomi House Children's Hospice
Noah's Ark Appeal
Northern Ireland Cancer Fund for Children
NSPCC
Radio Lollipop
Rainbow Children's Hospice
Rainbow Trust Children's Charity
Richard House Children's Hospice
Room To Read
Save the Children
Schools Outreach
Sheffield Children's Hospital
Shooting Star Trust
Sick Kids Friends Foundation
South Gwent Children's Foundation
Sparks
Spring Centre
St Andrews Children's Hospice
St Mary's Hospice
St Oswald's Hospice
Studio A D H D Centre
Sussex Snowdrop Trust
The Association of Children's Hospices
The Child Care Action Trust
The TreeHouse Trust
Tommy's, The Baby Charity
Tower Hamlets Education Business Partnership
Tros Gynnal
Tullochan Trust
Variety Club Children's Charity
Whizz-Kids
Wingate Special Children's Trust
Winston's Wish
Wood Street Mission
Yorkhill Children's Foundation
Zoe's Place