

Parish Church, Bolton-le -Moors

lssue130



23rd June 2019

The First Sunday of Trinity

PLEASE REMEMBER IN YOUR PRAYERS

Please pray...

LAMB

Jean Marlene Michael Doreen Minti Ronnie Carys Rachel John Johanna John Norma & David Bernard Lynn Andrew Will Barbara Wendy Yasmin Lynn Kirsty Sean Marlene Jennifer Steve

We come before you, O Lord, with nothing except the gift of our hearts in prayer. Hear us and bring us your peace.



Editorial

Oscar Romero was a Bishop during the 1970s in the troubled country of El Salvador where a violent Civil War took place. There was a huge division between the rich and poor and Oscar Romero was someone who used his position to denounce injustices and massacres committed against civilians and stand up for those who could not stand up for themselves. He preached sermons and strongly condemned the violence that was an everyday reality for many Salvadorians. He was considered to be a 'voice for those without a voice', in a country that was ravaged by the poverty divide. He said, 'Aspire not to have more, but to be more.' In a world where we can 'have' almost anything, how often do we try to 'be' that which this world needs most? Sometimes it is difficult and uncomfortable to stand up for what we believe in. Sometimes it is easier to go with the crowd, but ultimately that will not make much difference. Who can you 'be more' for today? Who can you be a voice for?

'Therefore, my beloved brothers, be steadfast, immovable, always abounding in the work of the Lord, knowing that in the Lord your labour is not in vain.' 1 Corinthians 15:58

Today's Service

This week is Together for God

Next week is <mark>Holy Baptism</mark> Readings are: Romans 5 vs.-14 - 17 & Luke 11 vs. 51 – 62

Today's Collect

God of truth, help us to keep you law of love and to walk in the ways of wisdom, that we may find true life in Jesus Christ your Son





THE CHURCH OF ENGLAND Diocese of Manchester



St Bede Charity Partner 2019;



News...

MAKING A DIFFERENCE STEWARDSHIP CAMPAIGN 2019 UPDATE

You may remember that in May; we launched a stewardship campaign 'Making a Difference' where we shared with you our need at St Bede's to increase our income by £4,000 per year to cover our current ministry costs and to help us develop our ministry; particularly by adding a projector and screen into church and to support our project to replace the toilet block and to improve our disabled access.

We are pleased to announce that due to increases in standing order giving and the money that we received through the gift day envelopes; our income has increased by £765 this year! Thank you so much for your continued and increasing support for all that we do here at St Bede.

Unfortunately, that still leaves us short of our target of \pounds_4 ,000 extra this year. Please do continue to pray about how you can support the work of St Bede's. If you wish to give by standing order, then please do speak to David Almond our treasurer.

Vinny

STOP PRESS

The latest day for submissions this week is Thursday



BIRTHDAYS

Melissa Fletcher - 13

Max Critchley - 4

Remember to add your own birthday to the list at the back of Church!



NEW COMPETITION!

A £25 M&S Gift Card is up for grabs in our new competition!! Watch this space for details in the coming weeks!



Our Church depends very heavily on fundraising as well as regular giving to keep our Church afloat. We work very hard to put on different events, but we need these events to be supported if they are to be successful in raising funds and providing opportunities to share fellowship as a Church.

As you have received, so may you be pleased to give.

St Bede's is a living Church and its people are The Church. The Church's only financial support is its own Church family.

Please try to support the social and fundraising events as they are vital not only to the financial wellbeing of our Church, but are great opportunities to get to know one another better.

Your Church thanks you for your gifts of money, time and talents.



JUBILEE AND COMMUNITY ROOMS

The Community Room and the Jubilee room are available to hire for parties, meetings etc. Please see one



Normanby Street, Bolton, BL₃ ₃QR



St Bede Parish Church, Bolton Le Moors of the Church Wardens, Gill or Jean

CONTACTS Priest-in-Charge – Rev Vinny Whitworth – 01204 658921 <u>vinny@st-bede.org.uk</u> Associate Priest – Rev Malcolm Bristow – 01204 659816 Church Wardens – Jean Philips – 01204 436023 Gill Blackburn – 01204 660396 PCC Secretary – Elaine Almond – 07757099862 Treasurers – David & Elaine Almond Organist – David Platt Newsletter Editors – Tony Whitehead 07967223380 & Sharron Hardman – 01204 700848 Social Media Team – Kirsty Critchley 07763 495009 & Tony Whitehead 07967223380 Administrator – Elaine Almond – 07757099862 St Bede Primary Academy Head of School – Sarah Rostron – 01204 61899 Chair of Governors – Tony Whitehead Vice Chair – David Almond



ST BEDE'S CHURCH, MORRIS GREEN, BOLTON-LE-MOORS @BedeParish,

newsletter@st-bede.org.uk info@st-bede.org.uk churchoffice@st-bede.org.uk

www.st-bede.org.uk

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DATES FOR YOUR DIARY...

Summer Fayre – Saturday 10th August – 1-4pm

Stalls will include;

Gift tombola, Sweet Stall, Children's games, Café with BBQ food and other food.

Please bring donations of goods for these stalls over the coming weeks!

Saturday Brunch – 7th September 2019 – 10-12

St Swinins Day Pledge commences Monday 15th July

Body Shop for Christmas – Thursday 17th October – 7.30pm in the Community Room with cheese & wine

Harvest Supper Quiz – Friday 4th October -7.30pm Ellesmere Club. Who can take possession of the coveted St Bede Harvest Supper Quiz trophy this year???







Rare Chromosome Disorder Awareness Week <u>16th - 21st June 2019</u>. 翁

A week to celebrate, educate and shine a light on all the special and unique people with chromosome and gene disorders.

As our chosen charity of the year a member of our congregation has chosen to share their unique journey...

It's that time of year again when my social media feed is littered with posts about chromosome disorder awareness week and I find myself being torn between wanting to share our "disorder" journey to help raise much needed awareness of genetic conditions like Max's and then wanting to keep quiet for fear of people who don't know him personally judging him based on his diagnosis.

In light of the fact that St Bede have so very generously chosen to support chromosome disorder charity, Unique this year I wanted to share a snapshot of our parenting journey as genetic conditions are becoming ever more common and if we can help just one family to feel a lot less isolated than we did when we got our diagnosis then it's a job well done!

Unique is a small charity supporting and informing families living with rare chromosome disorders. In 1993 the group was granted charity status and in 1996, Unique launched its comprehensive computerised database to collect information on how specific rare chromosome disorders affect the health, development and daily living of individual members over a lifetime. In 1999, Unique was awarded a 3 year grant by the National Lottery Charities Board to fund a full-time Development Officer and a part-time Family Support Officer and the group's first website was launched! Membership stood at just 1,192 families, by 2018, membership had risen steeply to over 16,500 families, representing over 18,500 individuals with a rare chromosome disorder with about 130 to 150 new families now joining each month!

When we were given Max's diagnosis of a rare chromosome disorder - in fact so rare it doesn't actually have a name, our paediatrician at the time had to digest enough information from a Unique leaflet to be able to explain the condition to us. Unique not only provide information on genetic conditions to families and professionals working with them but they also help put families in touch with other affected families for support which at a time of uncertainty is a huge relief.

Max was diagnosed just months before his 2nd Birthday. In a way we were relieved to find a cause for his unlucky streak of illnesses (he had various bouts of chest infections followed by pneumonia at 7 months old and always struggled to meet his baby milestones) but at the same time terrified of what the condition meant for Max and his future. The unique leaflet explained various ways in which Max might be affected as he develops and some of it was very difficult to read ranging from mobility issues, developmental delay to tumour growths. The early months were very hard and our endless appointments with various professionals didn't really enlighten us on how Max might be affected by his condition or what his future held - professionals are actually looking to us to help with research of such conditions. We were never sure if Max would walk and were once told "at least if he doesn't ever talk, he's so sociable and can communicate his needs". Max turned 4 on 21st June - he walks, talks (in fact it's hard to get him to be quiet!) and he starts mainstream school in September as a very able, confident little boy with his biggest supporters right behind him!

The exact cause of chromosome abnormalities is unknown, generally chromosome abnormalities happen during the development of an egg. In the process of cell division, the correct number of chromosomes is supposed to end

up in the resulting cells. However, errors in cell division can result in cells with too few or too many copies of a whole chromosome or a piece of a chromosome. Depending on which piece of the chromosome is missing/ duplicated determines how you're affected and this is extremely wide ranging.

I hate to say but in the early days I began almost mourning the perfect child I'd always dreamed of which somehow seemed to be being swiped from under our feet. You switch from wanting to know even the smallest of details about the condition to not wanting to know at all for fear of what you'll have to deal with. Then slowly over time learning that everyone develops in their own unique way whether or not affected by a condition and appreciating and celebrating even the smallest of milestones we were never quite sure we'd meet.

We've certainly learned to see the "able" not the "label" and couldn't be more proud of the happiest little boy that brings out the best in us and has taught us far more than we can ever teach him! After all God decided not to create us all the same - he's Max, he has the most amazing personality complimented by an infectious smile and is far more resilient than I could ever be.

We have had lots of ups and downs over the years so I don't say this lightly but Max's deletion has very certainly given us far more than it has taken away! He absolutely is a pleasure and makes us burst with pride every single day!!

If I had to give 1 piece of advice to other parents in a similar situation it would be to really embrace the unique way your child is blooming and to talk to others, you'll be very surprised how others are facing a very similar journey. I often think that if we didn't have Max's deletion to contend with, I'm sure there would be something else! Whilst our parenting journey isn't one we expected - we sure do love our tour guide!!

For more information about Unique visit <u>www.rarechromo.org</u>.

