



BRIAN WILSON: 1942 - 2025

BEACH BOYS LEGEND IS DEAD AT 82

By JOE MORGAN

THE Beach Boys' genius singer-songwriter Brian Wilson has died aged 82.

His masterpieces include Good Vibrations and California Girls.

Brian had dementia, and had long struggled with mental illness.

His family said: "We are heartbroken."

Full Story — Pages 12 and 13



How I made my bum look the



BY BIZARRE EDITOR ELLIE HENMAN

SEE PAGES 30 & 31

MIRACLE DRUG PLEA



Help us . . . Conor and Dean and, right, parents outside the Dail



By ADAM HIGGINS, Political Correspondent

PARENTS of kids suffering from a rare condition yesterday marched on the Dail calling for a new 'game-changing' drug to be introduced here.

Duchenne muscular dystrophy is an incurable disease that mainly affects young boys and can eventually cost them their ability to walk.

Brothers Conor, ten, and Dean Thompson, eight, both live with DMD. Dad Jamie said: "We need this drug. They need to urgently approve it, our boys don't have time to wait."

Full Story — Pages 10 and 11

Our boys don't

have time to wait

FAMILIES MARCH FOR MEDICINE SIGN-OFF



One of a kind

RADIO 1 legend Joe Duffy will bid farewell to Liveline later this month with a special edition of his favourite show.

The departing broadcaster is calling time on his decades-long career with RTE after announcing his retirement.

The 69-year-old will host his last Liveline on Friday, June 27.

And Montrose officials are bringing out all the big guns for his last show.

We can reveal organisers are planning 'the funniest of Funny Fridays' with the likes of Brendan O'Carroll and June Rogers expected to take part.

As well as being able to handle major stories of national importance, Duffy's ability to make the nation smile is one of the attributes that set him apart.

Despite being the face of RTE for many years, he never lost his touch as a man of the people of Ireland.

He has always seen himself as a bit of an activist. He was actively involved in student politics and served as president of the Union of Students in Ireland.

Joe famously led protests on campus highlighting a lack of access to education and spent two weeks in Mountjoy Prison as a result.

And he showed another side to himself when hosting The Meaning of Life, recording powerful interviews with important figureheads on their faith.

In short, Joe could do it all. Montrose chiefs have some very big shoes to fill.

RTE are determined to give Duffy the send-off he and his listeners deserve.

Govt drug plea

PARENTS of children with a rare muscle-wasting condition have called on the Government to introduce a new game-changing drug as a matter of urgency.

More than 100 youngsters are currently living with Duchenne muscular dystrophy, a genetic disorder, mainly affecting males, that causes progressive muscle weakness.

Families are now campaigning for the approval of a new drug, known as Givnostat, to be brought in.

Among those calling for it are Eilish and Mark O'Sullivan, from Co Donegal, who have two boys with the disease.

They are among many families pleading for the drug to be introduced to help give other youngsters a fighting chance.

Blast orders...

ASTRONAUT Dr Norah Patten has hatched a plan to avoid throwing up in space.

The Irish space explorer will enjoy a plain chicken wrap shortly before blast-off, but without much mayonnaise after a bad experience.

She doesn't want her lunch to boldly go where no lunch has gone before.



FAMILIES MARCH ON DAIL TO VENT THEIR ANGER



PLEA FOR HELP

Eilish and Mark O'Sullivan with a picture of their sons Nathan and Diarmuid and, left, Maeve and Michael Brogan with son Fionn

Every day is a lost day for these boys

We've seen what this drug can do in one boy
- MARK O'SULLIVAN

PARENTS WANT APPROVAL ASAP 'MIRACLE DRUG' HELPS EXTEND LIFE

Parents of children with Duchenne muscular dystrophy protest outside Leinster House yesterday

PARENTS of kids suffering from a rare muscular disease are pleading with the Government to speed up the approval of a new miracle drug.

One dad told us "every day our boys go without this drug, they lose a little bit more muscle".
Mainly affecting young boys, Duchenne muscular dystrophy (DMD) causes progressive muscle loss as sufferers grow older.
The life-limiting disease - which affects between 100 and 200 children in Ireland - results in kids losing the ability to walk and use their muscles.
There is no cure for the disease. However, a new drug has been invented that significantly delays the progression of the condition and gives children more time.
Eilish and Mark O'Sullivan, from Co Donegal, have two boys with DMD.
The family were told that their oldest son Nathan would lose the ability to walk by 12

and may not live past the age of 18. However, the GAA-mad youngster was admitted to a clinical trial in the UK for miracle drug Givnostat.
Nathan is now 21 years old and still able to walk after being given the drug.
However, nine-year-old brother Diarmuid is not able to access Givnostat because it has not yet been approved in Ireland - despite already being rolled out in other countries across the world.
Eilish and Mark joined around 100 people at a protest outside Leinster House yesterday, where families were pleading with Health Minister Jennifer Carroll MacNeill to step in and speed up the approval of this drug in Ireland.
Eilish told The Irish Sun: "When Nathan was diagnosed, we brought him over to Newcastle in the UK for a clinical trial back in 2016. "He's been on the drug ever since. He was previously told he wouldn't be able to walk by 12 and he could possibly lose his life by his 18th birthday."
"He is now 21 and he does the scoreboard for all the Donegal GAA matches in MacCumhaill Park in Ballybofey and climbs up and down the steps to do it."
"It is a miracle and we put that

down to the drug." His parents brought a dose of Nathan's miracle medicine to yesterday's Dail protest to highlight the heartbreaking situation where one of their sons can access this drug while his younger brother can't.
Mark said: "We've seen what this drug can do in one boy and yet in the same home the other boy doesn't have the same opportunity. "That is hard to explain to him because when the time comes he will ask 'how come my brother is 21 or 22 and I'm nine, ten or 11 and I can't walk but he seems to be doing OK.'"
The roll out of the drug in Ireland is incredibly time sensitive for children with muscular dystrophy as it has only been approved for use by the European Commission for children who can still walk.
Several parents at the protest yesterday told The Irish Sun they fear the HSE will take so long to approve the medicine that their sons will no longer be able to walk - and will then no longer be eligible for the treatment.
Conor Thompson, ten, and his eight-year-old brother Dean are also both live with DMD.
Conor has started using a power wheelchair as the muscles on his legs deteriorate, while his younger brother is still without the need for

a chair. Dad Jamie, from Dublin, told us: "This drug slows down the progression of Duchenne. We know it's not a cure."
"But every day our boys go without this drug, they lose a little bit more muscle and they will not get that back. This will change lives."
Mum Karen added: "Conor and Dean are amazing little boys. They are full of love for life. They make us laugh every day."
"We want them to live their best life for as long as they can. They enjoy life. They have great pals in school. They love swimming and playing with their brothers and gaming like all kids. They are so caring, thoughtful and loving."
"We really need this drug. They need to urgently approve it because our boys don't have time to wait."
"Every day is a day lost. They are using this in other countries all over Europe. There are early access programmes. There are compassionate access programmes."
"It is not fair to make our boys wait. They need it now. We don't have time. If Conor has to wait another year, the chances are he won't be eligible for this."
Nine-year-old Fionn Brogan, from Dublin, Access... Costello

was diagnosed with Duchenne six years ago. Mum Maeve told The Irish Sun: "Fionn is incredibly stubborn and determined. He's really behind the campaign because he wants people to see how strong boys with Duchenne are."
"We call them our warriors because they have to keep fighting. Fionn is at the stage where he is really struggling with things and finding steps and stairs hard."
Dad Michael is pleading with the Health Minister to step in and set up a pilot programme immediately to enable children to get access to this drug in the coming months.
He told us: "I want to see the commissioning of a pilot programme to expedite the rapid access of the drug."
"It is likely it could take up to two years to approve in our system here. We can't wait that long."
"There's no reason why the Minister can't intervene here immediately and introduce a pilot programme to roll out the drug now."
Una Ennis and her husband Kenneth were also among those who joined the protest at Leinster House on behalf of their son Archie.
Fianna Fail Senator Teresa Costello told us

she has written to the Health Minister to ask her to intervene with the situation and speed up access to the medicine.
She said: "It is out of the Government's hands at the moment as the manufacturer has to put in their application. I've engaged with the drug company and they said they are going to apply to the HSE so that should be in for July."
"I've written to the Health Minister to ask that this drug is made available through an early access programme because these families can't wait that average time of over 600 days for approval."
The HSE yesterday told The Irish Sun that they are aware of the plight of patients with Duchenne muscular dystrophy and are now waiting on the drug company to apply for approval here.
They said: "The company must now apply to the HSE for the treatment to be reimbursed through the public health system."
"If the firm, Italfarmaco SpA, chooses to submit a pricing and reimbursement application, the HSE will give consideration to the application with consideration for the criteria in the 2013 Act."
The Irish Sun contacted the Health Minister and drug company Italfarmaco SpA for comment.
adam.higgins@the-sun.ie

Demand... Una Ennis' son Archie suffers from DMD