

FIRSTLIGHT NEWSLETTER

*"People always ask, Oh, how did you get over it,
but people who have actually been through it
know that you don't get over it.*

You learn to live with it, and it does get easier, but you don't get over it."

Mary Kelly mother of Zoe Kelly who died on July 1st 2007 at just 28 days old

Rossbeigh Beach, Co.Kerry

MESSAGE FROM FIRSTLIGHT CEO

Dear friends and supporters of FirstLight,

It is wonderful to feel that following two years of restrictions we can walk outdoors together this June with family and friends to remember our loved ones who have passed away.

We have chosen Father's Day (June 19th) again this year as the day for FirstLight's Mile in Memory Remembrance Walks as Dads can often be the unforgotten grievers due to the societal pressure on them to 'keep it together for the family following the bereavement of their child.

Father's Day can be challenging for bereaved dads on the day and in the run-up to the day. If there are other children, it may feel difficult to join in the celebrations when missing the child who died.

If there are no other children, it can feel as if the bereaved Dad has lost his identity as a father. But, bereaved dads are still dads and it can be really important for them to find a way to keep a sense of connection with their baby or child who has died. We have permanent bonds with those we have loved, and their death doesn't bring an end to that bond. Even though we may miss them or the things we hoped to do with them, terribly, we can honour that bond and the love that remains.

Bereaved Dads are not alone and the upcoming Mile in Memory Walks provide an opportunity for them to meet other bereaved Dads and to remember their child who has died in solidarity with family, friends, and members of their community. The stories of some families who have found solace and support from their Mile in Memory experiences are recounted inside this issue.

We would love to see walks taking place on 19 June in all counties in Ireland. Included in this issue are details of how FirstLight can support you if you plan to organise a Mile in Memory Walk in your locality. It doesn't have to be a big event, so if you plan to go ahead with a Walk, do only what you feel is manageable for you and your family.

Covid-19 has been especially hard on families that have unexpectedly lost their child. In our experience, for many, their grief journey is only beginning now and we have welcomed an exceptionally large number of families who have sought support in recent months. We are absolutely delighted that Elaine Cunningham, a very experienced child and adult therapist who has worked as an outsourced therapist for FirstLight for a number of years, has joined FirstLight's core team as Clinical Services Manager. Elaine will work closely with Georgia Howard, FirstLight's Clinical Services Director, to provide support services to the families referred to FirstLight and those that have self-referred.

My sincere thanks to all who donate and fundraise for FirstLight. With the funds raised, it is possible for us to continue to provide our professional support services to a substantially increased number of families.

With ward regards,

Fionnuala Sheehan, CEO, FirstLight

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**National
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Number
1800 391 391**

FirstLight

Supporting Suddenly Bereaved Parents & Families

New Australian SIDS Biomarker Study



Researchers in Australia have identified a biomarker that could help detect babies more at risk of sudden infant death syndrome (SIDS) while they are alive. The research was led by Dr. Carmel Harrington, Managing Director of Sleep for Health and an Honorary Research Fellow at the Children's Hospital Westmeads. Her son Damien died from SIDS in 1991 and she has spent the past 29 years researching Sudden Infant Death Syndrome.

This is an interesting and important study and will require further research. FirstLight welcomes new SIDS research and hopes that it helps us understand more about why apparently healthy babies die without cause.

While this and other research continues to be undertaken FirstLight would urge all parents and carers with infants to continue following the evidence-based safer sleep advice to reduce the risk of SIDS occurring. This includes: always sleeping a baby on their back in a clear sleep space on a flat, firm, and waterproof mattress with no bulky bedding, pillows, or cot bumpers. This advice has secured significant decreases in the number of babies dying of SIDS.

If you would like additional information on Dr. Carmel Harrington's study, listen to an interview she has done with Miriam O'Callaghan on RTE Radio 1 on Sunday, May 22nd. You can find the Podcast on the RTE Player or www.rte.ie

New FirstLight Referrals Email Address

referrals@firstlight.ie

FirstLight has launched a new email address for submitting referrals which can be used by both families and frontline professionals. We will also be launching a new online referral form via the website www.firstlight.ie which will go live in June.

The new email address is referrals@firstlight.ie which goes directly to the Clinical Team.

FirstLight Expanding Counsellors' Register

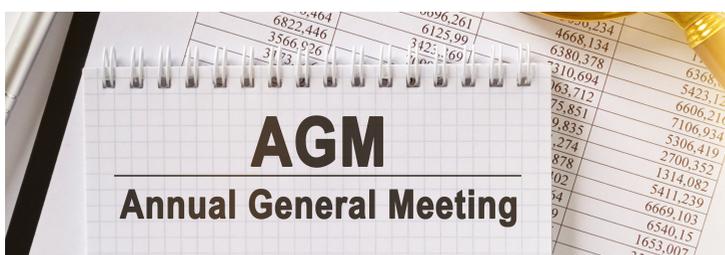


Demand for FirstLight's services in 2021 was the highest since the organisation was established 45 years ago, with 207 families supported nationwide. We are predicting a similar, if not higher, number in 2022.

For this reason, we are looking to expand the number of psychotherapists on the *FirstLight Counsellors' Register* across Mayo, North Dublin, Carlow, Kilkenny, Westmeath, Athlone, and Donegal, Kerry, Meath, Cork, Galway, Offaly, Cavan, Monaghan, Louth, Wicklow, and Leitrim.

If you are interested in joining the *FirstLight Counsellors' Register* please email andrew@firstlight.ie or phone 01-8732711

ISIDA AGM Meeting 2022



Notice is hereby given that the Annual General Meeting of the Irish Sudden Infant Death Association t/a FirstLight will be conducted by electronic means on Tuesday, June 21st, 2022 at 19:30pm.

If you would like to attend email info@firstlight.ie

Lord Mayor's Charity Ball Sets a New Record Raising over €125,000 For Three Charities



Top Row Photos L-R: (1) The Round Room at the Mansion House, (2) Norah Casey MC for the Lord Mayor's Charity Ball 2022, (3) Lord Mayor Alison Gilliland Host of the Ball.

Middle Row Photos L-R: (1) Fionnuala Sheehan CEO FirstLight, Meave and Oliver Blackwell, Chairperson FirstLight with Lord Mayor Alison Gilliland, (2) Georgia Howard, Clinical Director, FirstLight and her partner Adam French-Wollen with Lord Mayor Alison Gilliland (3), Irish Actors Byran Murray and Una Crawford O' Brien, FirstLight Patron with Lord Mayor Alison Gilliland

Bottom Row Photos L-R: (1), Contemporary Artist Ed Williamson adding the finishing touches to his Brian O' Driscoll painting which raised over €3,000 on the night. (2) Nora Murrin with her daughter and the Lord Mayor Alison Gilliland (3) Nazanine Nolan of Ruhama, Fionnuala Sheehan CEO FirstLight, and Cristina Santamaria of Aoibhneas

The Lord Mayor's Charity Ball on Saturday, April 30th was a tremendous success exceeding all expectations, raising over €125,000 in donations. This is a new record for the Ball and guarantees that FirstLight, Ruhama, and Aoibhneas will each receive over €40,000. These funds will significantly support the work of all three charities in the coming 12-months.

FirstLight's involvement would never have occurred were it not for the kindness of Larry and Nora Murrin, who so generously nominated FirstLight as their charity for 2022. Their son Larry died in 1990 from SIDS and following his death, they received support from ISIDA and its founder Eimear Berry. We also would like to sincerely thank every single person and company who so generously supported the Ball whether through purchasing tickets, donating raffle and auction prizes, or assisting with its promotion. A special thank you to Padraic O' Kane and his team at Corporate. ie, the Lord Mayor Alison Gilliland and her team headed by Fanchea Gibson at the Mansion House and Norah Casey who was an outstanding MC on the night.

Families, Friends, and Communities Coming Together in Solidarity



Since 2019, the *Mile in Memory Remembrance Walks* can take place in person for the first time. Due to Covid-19 restrictions around social distancing and group gatherings for the past two years, the event has taken place virtually. Families shared pictures and videos of their walks on the FirstLight Virtual *Mile in Memory Remembrance Walks* Facebook group. Individual family groups across the country walked in their localities even as far afield as Australia. It was an excellent example of communities finding a way to still support one another while having to stay physically apart.

The *Mile in Memory Remembrance Walk* is a very special event filled with love, laughter, and tears. It is an opportunity for suddenly bereaved parents and families and their entire community to come together in solidarity and support one another in a very difficult time. When it was possible to host the walks in person, groups went to beaches, parks, and fields. The walks provide opportunities to share memories and reflect. Some groups choose to include poetry recitals or picnics and refreshments as a part of the day.

The 2022 *Mile in Memory Remembrance Walk* will again be held on Father's Day, Sunday, June 19th, acknowledging the role of bereaved fathers within the family after the sudden loss of a child. There can be a lot of societal pressure on fathers to be strong, making it difficult to express grief. The *Mile in Memory Remembrance Walk* allows families to come together and support each other in their grief, surrounded by relatives, friends, and the wider community.

As this will be the first in-person *Mile in Memory Remembrance Walk* since 2019, we hope to have a walk across all 26 counties. To make this a reality, we require the support of families across the 26 counties to organise a walk within their county.

Would you Like to Host A Mile in Memory Remembrance Walk in your Area?

If you are interested in hosting a *Mile in Memory Remembrance Walk* within your area, FirstLight will provide you with promotional materials for the walk, i.e. t-shirts, wristbands, candles, and posters, and link you with other walks within your county. We can also support you with promotion via social media and through your local media i.e. newspaper and radio stations.

For additional information please contact Andrew Mernagh at the FirstLight head office on 01-8732711 or via email at andrew@firstlight.ie.

The last time I saw her, I can still see her so clearly, and she'll be 32 years dead in July



On July 12th, 1990, Una Crawford O' Brien's seventeen-week-old daughter Sorcha died of cot death. Recently Una spoke to Eva Conroy of FirstLight, where she told her own personal story and spoke about her role as a FirstLight Ambassador and patron of the *Mile in Memory Remembrance Walk's*

Could you tell us about your personal story, please?

July 12th, 1990, was a glorious summer day when even shorts and a t-shirt were too hot. And I was happy, very happy. I had a wonderful, energetic four-year-old son Tim and a beautiful seventeen-week-old daughter, Sorcha. She was the best, she smiled all the time, except when a camera would be produced, and then she would scowl, so in photos, she looked like a grumpy baby. But she was anything but; even the day before, my friend laughingly said that I would probably have terrible trouble with her when she was a teenager as she was so incredibly good now.

Sorcha was also a great sleeper, and on the evening of the 12th, she was due for evening feed at 9 pm. The fact that she didn't wake up was not unusual, and at 9.23 pm (*some facts stick in your head*), I went up to get her. And that's when my life changed forever. I don't have to explain how I felt; you have all been there. Disbelief, horror, shock, terror, dread. I always thought that heartache was something in novels, but it's not. The physical pain is very real. First thing in the morning, when you are barely awake, it's there. It eats into your very being. And when you finally get to sleep at night, it's the last thing you feel.

Honestly, I hated all the people who said, "time is a great healer". I didn't feel that I would be able to survive without Sorcha, but with a four-year-old who needed to be cared for, I had no choice but to keep going. I got through the hours, then the days, and finally the months, and very slowly, the pain eased. Her first anniversary was hard, but the anniversaries kept coming, and she will be thirty-two years dead this year. I still miss her and wonder what it would be like if she were here. I have two wonderful sons, Tim, and Fionn, who was born two years after she died. I always say three children if anyone asks because she is here with me always. Time is a great healer, I still have bad moments all these years later, but that's okay; I allow myself to feel.

Everyone who has had a child that died thinks about what could have been and what might have been. The last time I saw her, I can still see her so clearly, and she'll be 32 years dead in July, and yet if she was an adult, what would she be like so we all have those thoughts.



Una and her partner fellow actor Bryan Murray at the Wexford Mile in Memory Remembrance Walk in Wexford in 2015

How did you become involved with FirstLight?

My husband Brian contacted his doctor; he hadn't been too well the day before she died, so he'd come home from work early. He reached his doctor the next day; they told him to phone ISIDA, as it was known at the time. He spoke to Eimear Berry, who had started the organisation, and she was extremely helpful to him. We then met other people from the organisation, and they came out to visit us. They asked us questions as well because, at that stage, they were also conducting research into cot deaths, so they wanted to know Sorcha's history, besides everything else. That's how we found them first. And then a neighbour who we had never met had heard in the pharmacy that we had suffered a cot death. He called around with a bunch of flowers, and he had been involved with ISIDA himself as well, and we felt that it sounded like something that we needed, and that's when we contacted them.

Would you have any advice for parents who might have recently lost a child suddenly or who might be struggling with their grief?

I would say – talk to like-minded people who have also suffered death, to anyone who will listen. Your heart is so full of it at the time that it's all you want to talk about. Some people are afraid that they will upset people by crying, but it's the only way you can get through it by talking about it; that's my advice. Also, seek help in whatever way you can. Whether it is just by talking to somebody or by crying. The hurt is there, and it's very real, and you have to do whatever you can to try and ease it. I have so many photographs of her, and they're still everywhere.

What has your role as a FirstLight Ambassador meant for you?

I'm just glad to do something, no matter how small. I can't do an awful lot, but I know what it means as a mother. If people see me as Renee in Fair City and on the stage doing plays, they know that I still suffer from it. Her birthday is coming up, and she'll be 32, and I'll cry. I always do. As a FirstLight Ambassador, I just want everyone to know that there is always somebody else who also understands you and can hopefully help you.

What does the Mile in Memory Walks mean to you personally?

I love getting out on them because a group of people comes together, and you know they are there for the same reason- they have lost a child, and their heart was broken. Mothers, fathers, grannies, grandads, new children who arrived in the family, and brothers and sisters. It's great solidarity to know that we're supporting each other. We haven't been able to do it in person for the last couple of years, my last memory was the one in Clontarf. It was such a big crowd, and we were all there for the same reason. And people were laughing, and people had just had recent bereavements; it's life, and we are all there for the same purpose.

My biggest aim would be to see a Mile in Memory Remembrance Walk in every county, like Darkness into Light



Mary and Ger Kelly on the far right with their family at Rossbeigh Beach Mile in Memory Remembrance Walk in 2018

On July 1st, 2007, Mary and Ger Kelly's daughter Zoe Anna died of cot death in her mother's arms at just 28 days old. For the last 10 years, Mary and Ger along with their children, family, friends, and the community of Glenbeigh in Kerry have been hosting the *Rossbeigh Beach Mile in Memory Remembrance Walk*. Recently Mary spoke with Eva Conroy of FirstLight where she discussed her family's personal story and involvement with FirstLight since 2007.

Could you tell us about your personal story, please?

We had three children, Michael, Katie, and Cathal; then, I had a miscarriage a few years after Cathal decided to call a halt as we had three children who were happy, they were healthy. Then I found out I was pregnant again at the age of 40; I thought do I need this now? But I came to terms that I was pregnant, that I had a living being inside me. On the 4th of June 2007, I had the most beautiful baby girl. 9lbs, she was healthy and beautiful, and the lads were crazy about her. Zoe Anna was her name. My other little girl was 13 at the time and was delighted with her baby sister; what else could a 13-year-old want. We brought her home, and she was healthy, breastfeeding, and sleeping through the night; she was the nicest birth out of all my children. We couldn't have asked for more. When we brought her home, I will never forget the weather; it was beautiful. It was too warm to dress her; she was going around in a little vesty. She was everywhere: she was at the beach, she was in the school, she was at the shop, she was in the church, she was everywhere. The other kids were completely in awe of her. Michael was 17, Katie was 13, and Cathal was 6 and a half.

On the night of July 1st, we put her to bed. I took her up at some hour of the night to feed her as I was breastfeeding and I kind of dozed myself, and as you can imagine, you can't really sleep while breastfeeding. Zoe Anna died in my arms. It was like our whole world was turned upside down. It destroyed me, my family, and my daughter; luckily, we were strong; we had a strong marriage and a strong family composition, and we got through it. It was challenging, my 13-year-old daughter was in awe of her baby sister, and she just withdrew, and I had that worry on top of the loss of our baby. And I would never say my baby because she was my husband's baby too, she was the lad's baby sister too, and it was a massive thing to happen. It's only when it comes to your own doorstep that you realise what it's like.

How did you become involved with FirstLight?

When we were taken to the hospital that day, we met a nursing manager Gerard Coonihan, I'll never forget him. I don't know where he is today, but I'll never forget him; he recommended FirstLight, ISIDA at the time, to us. He gave us the paperwork and literature going home. When we came home, we got a phone call from an extraordinary lady Ger O'Brien, I don't know what she's doing now, but she was a big part of ISIDA. She brought me through it, my husband through it, and them all through it.



She was only after losing a son of her own; she had lost a son through SIDS many years previously but had also lost her other son in a car accident just a few months before she visited us. She sat with me for hours and just spoke through everything. After a couple of months, another lady picked it up, Deirdre Dowling – they were our lifeline. ISIDA were our lifeline, and I can't recommend them highly enough. Even today, we feel we can pick up the phone to FirstLight if I was having a bad day and say I need to speak to someone.

If we didn't have people throughout the years who could speak to us where we were at and understand what we were going through, I don't know what we would have done. People always ask, " Oh, how did you get over it, but people who have actually been through it know that you don't get over it. You learn to live with it, and it does get easier, but you don't get over it.

Would you have any advice for parents who recently lost a child suddenly or who might be struggling with their grief?

My big thing is that I didn't retract back into myself; I talked and talked and talked to anyone who would listen. Anyone who would pick up the phone. There are supposed to be 5 stages of grief, but there are 25 stages of grief. There are so many different stages of grief; it depends on your family composition and who you are. I was so angry. I thought we were good people; we're always involved with a charity, do what we can to help others, and are hugely involved with the community. I just thought, why has this happened to us? I thought I would never get to the place of acceptance. Talk. If it has nowhere to go, it will cause severe internal grief. It gets easier, you never get over it, but you learn to live with it. Of course, birthdays, anniversaries, and Christmas bring it back again but talk about it.

Take time for yourself. Be good to yourself, be good to yourselves as a family, and don't forget the dads and other siblings; I found that the focus was on me. When I first went out after it, someone came up to me and said Oh, Mary, I am so sorry for the loss of your baby; my husband was right next to me, and I remember thinking he was her dad. He was as much a part of her as I am. Dads and other siblings can be forgotten. It takes time. No one can say it'll be ok after 6 months, or it will all be ok. It takes time, and everyone is different. We were also blessed on October 28th, 2008 with the birth of our beautiful son Sam. I have a husband and three other children.

There is no known cause for SIDS, but I questioned myself repeatedly until one day, it clicked that I have three other children and that I am a good mom. There is no known cause for it; it is just one of these unfortunate things.

I have created a cupboard with her pictures and her footprints in the corner of my sitting room. Every morning, one of the lads or I turn on the light and say good morning and every evening, we turn it off and say goodnight. We talk about her every day; we talk to her every day; she's a big part of our lives. We had a bench erected for her on Rossbeigh beach as well. Where we can go and sit when we have our walk.

You have been hosting the Rossbeigh Beach Mile in Memory Remembrance Walk for over ten years. Could you tell us what is involved in arranging a Mile in Memory Remembrance Walk and what advice would you give someone hosting their first walk?

Ger O'Brien (*FirstLight's former Clinical Manager*) rang over 10 years ago and said ISIDA had an idea for the Mile in Memory Remembrance Walk. I thought it was the best idea ever and talked to my husband, we decided to do it the first year and had the most fantastic turnout. They sent down loads of flyers and things from Dublin and we advertised it, and we didn't know what we were doing the first year. We advertised it in church, school, local paper, pubs, and restaurants – had a fantastic turnout from local people. In later years we put billboards up on either side of our village. We do ours on a beautiful blue flag beach, so we have that beautiful facility right on our doorstep. Get people to rally around, our neighbours friends and family contribute tea and goodies – make a day of it. People just love it. Facebook is great for advertising. People come from as far as 40 and 50 miles away.

The emotional side of it can be very tough. Before the walk, we had a remembrance service. We found that nice, and it was special, but it was challenging emotionally. There were candles, songs, and readings, but I couldn't get through it without crying.

MILE IN MEMORY REMEMBRANCE WALK, FATHER'S DAY JUNE 19



Community of Glenbeigh with Mary and Ger Kelly at the Rossbeigh Beach Mile in Memory Remembrance Walk in 2018

The walk is out in the fresh air, and people you had no idea had this going on in their lives. People who might have lost a baby through miscarriage through stillbirth. For the 1st walk, emotions can be pretty high. Still, you will be amazed at the support you will get, and also when you look around and see the other people, you are doing it for yourself and other people. It's a special day.

Advertising, get on to FirstLight; they will help you and give you advice; everyone has to start somewhere. Mary's sister has never been able to make it but will be coming this year. I love that it happens on Father's Day, involving the dad and making it about the dad rather than always about the mom. Of course, there are some situations where there might not be a dad or he might not be involved, but for a lot of families, it is lovely to have it on that day. Just to say to the dads, you're not forgotten about.

This year is the first time in two years that the Mile in Memory Walk will take place in person, what words of encouragement would you give someone considering hosting a walk in their area?

We did it the past two years just as a family, but we did it virtually. Everyone we know basically got involved in their own areas. I'm not one for technology, but my daughter and son set it up, and we raised € 1,000 in both years, which we were so surprised about.

I can't wait this year, I'm already organising it. After what we've been through these past years, not being able to get out, I would love to see walks in every county in Ireland. I think FirstLight is such a fantastic service. I'm so proud that in our small community, Andrew Mernagh, FirstLight's General Manager, told me recently that we have raised over €20,000. I can't wait to read out the letter saying that when we have our next walk and say this is where our money is going, this is what it is helping.

We dedicate the walk to Zoe and all other children and anyone who has lost a child. Some people call it Zoe's walk, but I don't personally because it's not just about Zoe. One couple who joined us had lost their son, and he was 40, but he was still their son. Another parent had several miscarriages, another parent had a stillbirth, another parent lost their child in a car accident, and another parent had lost a child through suicide. You never know what is going on in people's lives. Everyone comes for their own reasons, but it's a communal thing. I come away from it, and I just think I wouldn't be a part of this if it weren't for Zoe.

Make the rest of the day a family day. On Rossbeigh beach there is a little shelter and we and the neighbours do teas and cupcakes and buns and the children absolutely love it. It's a very significant event in our lives. Really looking forward to this year coming.

My biggest aim would be to see Mile in Memory Remembrance Walk in every county annually, like Darkness into Light. It would be lovely.



Mile in Memory Walk 2022, Sunday, June 19th

- FirstLight's annual Mile in Memory Remembrance Walk will take place on Father's Day Sunday, June 19th nationwide. If you would like to host a walk in your area please [email andrew@firstlight.ie](mailto:andrew@firstlight.ie) or phone 01-8732711

VHI Women's Mini Marathon, Sunday, June 5th, 2022

- The Vhi Women's Mini Marathon, an annual 10k charity road race, occurs each June bank holiday weekend in Dublin and is the largest Women's event of its kind in the world. In 2020, due to Covid 19, the Vhi Women's Mini Marathon went virtual for the first time. The event took place in October 2020 and attracted over 22,000 entrants from all over the world and again in 2021. In 2022 the event is taking place in public once again. For further details: www.vhiwomensminimarathon.ie

Baby Loss Awareness Week is held annually from 9 to 15 October

- An annual collaboration between more than 60 charities across the UK and Ireland, Baby Loss Awareness Week aims to raise awareness about the key issues affecting those who have experienced a sudden loss of a child. For further details: www.babyloss-awareness.org

Global Wave of Light Saturday, October 15th, 7:00 pm

- Please join FirstLight for the Global Wave of Light Saturday, October 15 at 7 pm. Baby Loss Awareness Week finishes each year on October 15 with the global Wave of Light'. October 15 is also International Pregnancy and Infant Loss Remembrance Day and is recognised across the world. Simply light a candle at 7 pm local time and leave it burning for at least 1 hour to join us in remembering all babies that have died too soon. For further details: www.babyloss-awareness.org

Irish Life Dublin Marathon, Sunday, October 30th, 2022, 8:45 am

- By the time the next Dublin Marathon comes around on October 30th, it will have been three years since the race took place. The entry number is capped at 25,000 and everyone who signed up for the 2020 edition had the option to either keep their spot until the race returns to the streets or get a full refund. Very few took the refund. For further details visit: www.irishlifedublinmarathon.ie

National 24-Hour Helpline Number 1800 391 391

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www.firstlight.ie: Charity No. CHY7716

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