

Vojo's Story

Charles Storer (our Treasurer) and his partner, Bev who have worked to hard to bring about a happy ending to Vojo's story and visited Vojo for the weekend 8/9 January 2005, and this is the news they brought back:

Vojo Despic

Update.....February 2005

Charles Storer and Bev Gadsdon went to visit Vojo with his new family in Italy in January 2005 and had an amazing time!

Vojo has been exceptionally lucky to have found such a loving, fun and welcoming family, by the time we left we felt that we had known them for years and do hope that we can return some of the hospitality if they ever visit the UK..... Which we hope they will!

Following Vojo's adoption from Gornja Bistra, Croatia just over a year ago Charles and I have been anxious to see him again and we could not have wished for it to be any better.

Vojo is now eight years old and lives in a gorgeous 'tiny tiny' village in the Frascati region of Italy in a town which is twinned with Gornja Bistra. He lives with a great family – Elena, Loredana and Laura in a great house with sofas – which he was very excited about as he had never seen sofas before. He has a great network of friends and everyone at the village certainly seem to adore him too!

He now attends a local school and is fluent in Italian and tried to teach us to count (we are still learning!)... Luckily for us Loredana and Laura speak great English!!!

Vojo is excelling at school and has some great new friends.

His condition ([Epidermolysis Bullosa](#)) looks to have improved with the loving attention that he receives and excellent medication which available. Charles and I were very honoured to be there with Elena, Lory and Laura changed his bandages, a ritual that they endure every other day, taking approximately three hours. Voja was just amazing and an extremely brave boy.

Elena, Lory and Laura met Vojo when they went to volunteer at Gornja Bistra Hospital with the local charitable organisation "The Blue Roses Garden" (for more information please visit their website: www.volincontro.it) They are an amazing group of volunteers who help children both in Italy and regularly visit Gornja Bistra to assist and spend time with the children there.

Vojo is hoping to return with them next year for a holiday and to visit his friends. His friend and caring nurse, Borka, has been to see him from Croatia and phones regularly to see how he is.

Please see the following photos that show Vojo in his new surroundings and I think you'll agree, he certainly seems to be having a ball in Italy!!!

The following tells how this heart-warming story began.



Vojo at the hospital in Gornja Bistra

The "story"

"I first met Voja in 1999 when he was a tiny baby. He had only been at Gorna Bistra hospital (about 10 miles north of Zagreb) for one week. As I walked sorrowfully through the rooms of the hospital, trying to hide my almost uncontrollable urge to cry, I heard the faint protesting screams of this little boy. The nurses were, roughly, (or so it must have seemed to him), taking off his dressings, and placing him in a bath of water. His tiny little fingers were trying to push them away, but he soon calmed down, and like any baby began splashing about in the water. He gasped every time the water hit a new part of his body.

Like all Epidermolysis Bullosa (EB) sufferers, and I have now got to know and love quite a few, he was covered in bloody sores, and blisters of skin, from head to foot. In his hair, his ears, on his arms and legs, and on his back. Typically, some parts of the body are seemingly unaffected, but that doesn't last. I've known of the skin being torn right back to bare bone by accident just by catching the skin when removing dressings, but thankfully this is rare.

EB can, like many diseases, be more severe in some, than in others. In Voja's case, it is quite severe. Typically among EB sufferers, Voja's fingers have already (two years later) begun a process of decline, which results in the fingers closing into a fist, with a covering of skin, and only a pinch between the thumb and the rest of the hand for a grip!

Vojislav (or Voja as everyone calls him) is a delightful, bright, intelligent, captivating, and mischievous six year old, in fact everything he should be at that age...apart from the fact that he is exceptionally sick!

He has a rare skin disease called EB, and his skin bleeds and blisters, internally as well as externally, for no apparent reason.

When he was a young baby, his mother put him in a hospital for very severely deformed and mentally ill children. The hospital is poorly funded, and understaffed. Voja now lives there, unable to communicate with the other children, all of whom have either Spina Bifida or Hydrocephalus. He never sees his mother or any other family members, and yet, he always smiles!

Voja desperately needs mental stimulation if he is to grow up and have any sort of life. He needs to be able to mix with other children who can talk and play with him. He needs someone's love like any normal child.

Hope and Aid Direct has located Voja's mother, and she has asked that we do whatever we can to get help. She is a gypsy, and her home is not much more than a ramshackle and dusty old building. It could never be clean enough to support Voja's needs



Hope and Aid Direct wants (with Voja's mother's permission) to find either a specialist residential school for young children with disabilities, or a wealthy and caring family (or benefactor), who would like to foster/adopt and/or pay for the medical care that Voja so desperately needs.

Hope and Aid Direct is contacting various organisations, both in Croatia and elsewhere, to seek help.

Hope and Aid Direct has started The Vojislav Despic Fund so that Voja can receive financial support until such time as other long term help can be provided.

My feelings and determination to seek help for Voja stem from my friendship with other EB sufferers, Julia in the UK, Natasha and Tomislav, and Danny in Zagreb, all of whom I met through and as a result of 'Maggie', in Zagreb. Margaretta Gasic! Bossy, stubborn, confident, intelligent, and brave as hell! Maggie's story will help to explain why we MUST not let the same happen to Voja!



Her only verbal communication was with the nurses and doctors. The hospital is in the middle of nowhere, in the foothills of beautiful hills, but it is austere and unwelcoming, and all the children's rooms, which are shared, are on the first floor. A lift has only just been installed thanks to an American organisation. However the floors are made of cold stone, and there are not enough nurses to be able to ensure that the children are all taken outside into the fresh air.

Maggie, for most of her life in Gorna Bistra, which was her home till she was 18, never had a room of her own, and often lived in one of the corridors. She had a bed, and if she was lucky a cupboard, but no locks or privacy.

Hope and Aid Direct, along with one or two other similar organisations, have been supporting and trying to improve the situation at Gorna Bistra for some years. It is now greatly improved, but still very much in need of continued support with disposable nappies, baby clothes and sanitary items, but at the time of my first visit in 1996, they did not even have washing machines.

I had been asked to take medical gauze for a child that had to be wrapped in it from head to foot 24 hours a day. They had run out! Little did I know at the time, that it was for Maggie.

On my second trip 6 months later, while walking around the hospital rooms, I spotted a teenage girl, with what appeared to be very bandaged hands, sitting at a small table hitting the keys of what could have been a children's typewriter. I later found out that it was Maggie!

A few months later, in October 1997, Maggie was flown over to London with another aid worker who spoke English and Croatian (by an organisation called DEBRA which tries to care for and help EB sufferers) for an operation in St Thomas' Hospital, and I went to visit her. We started to communicate with lots of arm waving and smiles, but we soon became friends, and I visited her at least twice a week for the duration of her stay, often taking her out in her wheelchair to see and experience the sights of London (well actually the bars!) In just three months, she taught herself enough English to put us all to shame, AND boss around everyone in sight!

The 'operation' was a pioneering one, to open up one of her hands, and to separate her fingers again. She also had an operation on her leg. Maggie had not walked or used her hands properly to hold anything for many years! ...On Christmas Day, 1997, I was with her in the hospital when she managed to pick up a pair of scissors, and cut a piece of paper which I folded, and she cut again, before walking the entire length of the ward corridor. It was quite something, and very emotional!

As I had got to know Maggie during the first few days of her stay in London, (the first of several trips to St Thomas' for operations) I learned that she had saved all of her money for a long time before making the trip; she had wanted pocket money, and had saved the total sum of £30, but just days before leaving Zagreb, someone at the hospital had stolen it! This was not untypical of what had often happened. She had never had her own room, or anywhere to lock up her own possessions, as a consequence of which, she owned virtually nothing of her own apart from a few clothes!

As the time approached for Maggie to return home at the end of her treatment, early in 1998, we were all shocked to learn that Gorna Bistra hospital had stated their refusal to take her back! She was now 18, and would have to find somewhere else to go! How?

Through the support of people at St Thomas', along with [DEBRA](#) and I suspect Natasha's family in Zagreb, (Natasha was one of Maggie's closest friends in Zagreb - also a sufferer), eventually, a residential school for older disabled children was found in Zagreb. Initially however, Maggie had to go back to another hospital that agreed to look after her. The trauma of having to go back to somewhere unknown, by herself, when Gorna Bistra had been her 'home' almost since birth, must have been terrible!

Maggie's story has had amazing twists and turns since I have known her, but it has a fairytale ending. Natasha's mother eventually managed to persuade the Croatian Authorities that Maggie's father, who died during the fighting, was a war hero, and that because he had left a dependent daughter (actually abandoned her virtually at birth) the Authorities should provide for her. In 2000, they gave her a flat in Zagreb, and the money to go out and furnish it in whatever way she wanted. She again showed us all how special she really is, by choosing furnishings and furniture that make it probably one of the nicest and most desirable flats in Zagreb!

Vojislav meanwhile is still in Gorna Bistra Hospital, growing up in exactly the same isolated way that Maggie had . Imprisoned in a building surrounded by others who cannot communicate with him..."he must not be allowed to face the same horrors that Maggie has had to face!"

The Easter 2002 Spring Hope convoy allowed us to take virtually a tonne of baby food (kindly donated by Nutricia) to Gorna Bistra Hospital where Voja lives. The food was very gratefully received, and of course we stopped and played with Voja and some new toys we took for him. To our delight, we discovered a number of improvements. An Italian Aid organisation has decorated many of the rooms, with pretty picture rails to brighten the white walls, and new cots have been provided with new sheets and clothes for all the children.

The Croatian Government has provided funding to undertake badly needed roof repairs, but even more exciting was our discovery of a newly installed lift from ground to first floor. This will make a massive difference, allowing all the children to be taken downstairs and outside in the fresh air, at least occasionally during the summer, something that has been almost impossible in the past. We understand that an American Aid NGO has been involved, and provided funding for the lift, with the involvement in some way of the Croatian Prime Minister's wife, who we understand is herself an American. Imagine how pleased we were to see a picture of her with Voja in the main reception hall. We've no doubt that she will remember Voja, so our next step, having had no luck through either International Social Services, or the DEBRA organisation, is to contact her, Mrs Racan, to see if she has an interest and is able to help us in our quest to get Voja out of there. We will provide an update on our progress as soon as we can.

This appeal has had a very successful outcome, Vojo has been adopted and is living with his new family in Rome.

We recently received the following email from Vojo's new sister. I am sure everyone is delighted to from them and we all look forward to seeing some photographs of Vojo in his new home.

"Mr Charles Storer,

I'm Laura, Vojo's Italian sister. I can read English but I speak it not very well. Vojo is in Italy with me and my little family: my mum Elena (and now Vojo's mum too) and my sister Loredana. He is arrived on nine of December and we hope that it's for ever! He's in a good form, in spite of his serious disease. We are very happy to stay with him because he's a loveable baby.

He goes to school and he's a very good student. He's happy to live with a family, in a real home. we are also happy to meet you, if you decide to come to Italy! It's good idea, for us, to meet Vojo's friends. we'll send you soon a letter and Vojo's picture.

see you soon,

with love Laura, Vojo, Elena and Loredana"

Vojo happy in Italy



Vojo and his new family



Chas and Vojo, very happy to see each other again



Like all children of his age, Vojo loves computer games



A budding Barry Sheen?



Or maybe Spiderman?