



## VIVRE AVEC LE SED FAIRE CONNAITRE LE SYNDROME D'EHRLERS DANLOS

### NEWSLETTER

VIVRE AVEC LE SED  
Association reconnue d'intérêt général  
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## SED'ACTU

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### *THE VACATION TIME IS COMING*

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If I take up the opening words of last month's editorial: in May, do as you please, everyone can see that we unfortunately did with what we could, and the weather was not with us.

Our association's Moselle headquarters had its feet in the water, and believe me, the grass is very green. Our thoughts go out to the people, especially in East Moselle, where the Franco-German rivers burst their banks and caused major material damage. Fortunately, there was no loss of life, but these rainy episodes leave their mark.

In terms of actions, we had to cancel our participation in the Accessibility Day at LONGWY in Meurthe et Moselle, which had been scheduled for 17 May, the day with the heaviest rainfall.

Although the holidays are approaching in June, there will still be plenty of activities, which you can find out about in the 'Upcoming events' section.

As far as the Chairman and Vice-Chairman are concerned, we'll be taking a short break from the telephone and computer for a few days, from 24 June to 2 July. We'd be grateful if you'd get in touch with us when we get back, so that we can take a step back and decompress.

The first few days of July will be devoted to touring the Moselle schools for the last collection of the

year. As with every operation of this kind, we'll be hiring a van to bring back all the bags of corks collected. We have new partner schools, all of which have been awarded the 'eco-school' label. Their educational project focuses on ecology and sustainable development, and it's in this context that several schools have approached us. And as we say at every event, we teach children to LIVE TOGETHER, to accept others, their differences and their disabilities. The richness of these exchanges encourages us to continue.

We'd like to introduce you to Abelrhamen, who was diagnosed with EDS in France and has been living in the United States for the past two years with his mum. We've known them for a long time, we've met them several times and their story deserves to be told.

## PAST ACTIONS

- 13 May: Last meeting at Basse Ham school. As we said in the editorial, children always surprise us!
- 14 May: Ste Ruffine and Jussy schools, two small villages very close to Metz where the pupils learn in a relaxing setting, far from the noise of the city, a good start to growing up.
- 18 May: Invited by UDAF Moselle to take part in Family Day, the event was held on Place d'Armes in front of the Town Hall and the Cathedral, and the weather was more than generous compared with the day before!
- 24 May: A convivial moment with our friends and partners from BOUCHONS BONHEUR. The garage, where the corks were stored, was emptied, everything was sent to Alsace and we shared lunch together.
- 27 May: Off to POISSY in the Yvelines to meet the future orthopaedic surgeons in training at the ACPPAV. This institute trains future pharmacy assistants and care assistants, among others. 2h30 of constructive discussions. Caught up in our discussions, we didn't take a souvenir photo! Next year, I promise!



## UPCOMING ACTIONS

- 03 June to 8 June: A full week of travel in the Rhône Alpes Auvergne region. We'll be starting with the 22nd edition of the HANDICA trade show, where you can find us on stand G 39 in Hall 2 of the EUREXPO Park in LYON. It's an unmissable event, and as long as our cash flow allows it, we'll be taking part in these trade shows for the general public and professionals alike. The show takes place on 5 and 6 June. We will then head to CLERMONT FERRAND, where we will meet professionals and families we have supported, and we will finish in the Allier department, again to meet families and professionals.

- 10 and 11 June: Barely back home, we're off to Alsace at the invitation of the OBERNAI Lions Club, to present our commitment and actions. The presentation took place on Monday 10 June and on Tuesday 11 June we visited our volunteer friends at BOUCHONS BONHEUR in Bischoffsheim.

- 15 June: We'll be taking part in the SOLHAND collective's annual day of conferences, debates and reunions with member associations in Paris.

- 17 June: 2 events on the same day at the same time, so we'll be doubling up with a participation in the METZ PLAGÉ press conference, where we'll be this summer as part of our 'sustainable development' initiatives, and a meeting at the METZ CCAS to set up a 'bouchons' partnership.

- 19 June: Appointment at the PAMbio shop in PONT A MOUSSON (54) to present our association and consider a project for the shop's customers. PAMbio is a cooperative society with 180 members, and the meeting was organised by Mme DELIZE from Familles Rurales.

- 21 June: First school collection, before our summer break.



## FOCUS ON

*As we said at the end of the editorial, here is the portrait of the month, a special and touching story of this young boy Abd Elrahmen and his mum Sandrine.*

*We've known each other since 2017, and we've always tried to provide a sympathetic ear. We have raised the awareness of many people involved in this case, which has serious consequences for the development of this young boy, who was placed in a home at the age of 7. His mother was accused of Münchhausen syndrome by proxy (a psychiatric illness), and the expert report was negative, but her son stayed away from her for several months.*

*Everything came to a head when the PRM doctor who had been monitoring her son left his post, and with no trusted person to do so, the family was once again caught up in a vicious circle.*

*Their carefully considered decision led them to leave France and move to the United States and California. I'll let you read the mother's story, and we're proud to see Abd Elrahmen's progress. He was recently rewarded by his school, and next year he'll be joining a cybersecurity section.*

**Portrait of a 14-year-old French boy who crossed the English Channel to reach the Pacific Ocean**

**We left France at the beginning of 2022. The reason for our departure was the departure of our doctor and administrative pressure, with the threat of a new placement.**

**We began our adventure in California without knowing a single American word or understanding the system. I only knew America from the TV series and here we were in an unknown world.**

**In France, we were diagnosed with EDS, autism and dystonia.**

**Today in Los Angeles, we discovered that he has hemiplegia, epilepsy and another genetic disease. Diagnoses made in France have been validated in California. My son needs a manual and electric wheelchair, and assistance such as paramedical care.**

**Abd Elrahmen has just completed his 8th year at secondary school and attends mainstream education. He is going to take a 'cybersecurity' course to become an ethical hacker and track down hackers, so he could work for the FBI, CIA or DIA in the future.**

**He won two awards for being accepted into cybersecurity and biliteracy (similar bilingualism) after quickly acquiring a good level of English for an immigrant.**

**The American school system supports the inclusion of students with disabilities and encourages them to participate in society. EDS and autism are recognised in schools and hospitals.**

**The after-effects of the court cases are far from forgotten, but we are moving forward, it's a new life.**

**Thanks to the internet, Abd Elrahmen is able to talk to his father in France every day.**

**We also talk to Monique and Alice, who have supported us from the start.**









## HOW TO HELP?

Many of you want to join us by supporting our actions, our travels, our ministerial meetings, our trade fairs, congresses, presentations in schools, etc.

We have chosen to support clinical research rather than genetic research, and we are in favour of comprehensive patient care that includes listening to patients and providing them with appropriate treatment such as physiotherapy, posturology and proprioception.

You can help us by becoming a member of our association, simply by paying the basic fee of €10.00, renewable at the beginning of each year. You can also pay a larger amount and receive a tax receipt. Businesses can also support us through sponsorship.

Payments can be made by cheque made payable to VIVRE AVEC LE SED, or by credit card directly on the CREDIT MUTUEL website, <https://www.payassociation.fr/vivreavecledsed/paiement>.

Tax receipts are issued for individuals at the end of the calendar year.

You can also purchase the association badge for €3.00 or the VIVRE ENSEMBLE sticker for €2.00.



**VIVRE AVEC LE SED** est une association loi 1908 à but non lucratif reconnue d'intérêt général. Son siège est au 14 B Rempart Saint Thiebault à Metz (57000) – tél : 06 83 34 66 16. [www.vivre-avec-le-sed.fr](http://www.vivre-avec-le-sed.fr) - mail : [vivreavecledsed.asso@gmail.com](mailto:vivreavecledsed.asso@gmail.com)  
*Le syndrome d'Ehlers Danlos est une maladie héréditaire orpheline qui se traduit par une anomalie du tissu conjonctif en raison d'une altération du collagène et qui provoque entre autre une hyperlaxité ligamentaire*

- ☐ Je suis déjà membre et je renouvelle ma cotisation pour 2024, je verse 10 €
- ☐ Je deviens membre de Vivre avec le SED pour l'année 2024 je verse 10 €
- ☐ Je fais un don supplémentaire à « VIVRE AVEC LE SED »

Chèques à libeller à l'ordre de « VIVRE AVEC LE SED » - dons en ligne depuis notre site sur HELLOASSO ou sur notre site du Crédit Mutuel : <https://www.payasso.fr/vivreavecledsed/paiement> – paiement sécurisé

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Les particuliers peuvent déduire de leurs revenus le montant de leurs dons dans la limite de 20 % du revenu net global, les entreprises peuvent déduire 66 % des sommes versées dans la limite de 5/1000<sup>ème</sup> de leur chiffre d'affaires H.T. Un reçu fiscal sera délivré.

## CONTACTS & PARTNERS

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