

## Editorial

"My son runs away when he feels a strong emotion", "My daughter demonstrates repetitive behaviours", "My son behaves inappropriately in a social environment", "My son can no longer stand the feel of his clothes on his skin", "My daughter goes to sleep when she is in a group", "My son has poor time awareness".

Beyond seizures which represent a daily concern for our children, these are the changes in behaviour associated with refractory epilepsy and are symptoms which followed the onset of the illness which we would also like to "treat". It is hard to obtain a satisfactory overview of this subject and as parents we don't always know what information to cling to. One of the children cited above was diagnosed as being on the "autistic spectrum". In fact more or less all of the behaviours listed above have a link to this disorder.

This is what Dr Lagae confirms explaining that we still don't know why there is a link between FIRES and autistic type behaviours. In order to gain more understanding, we must act. As parents of children with FIRES we can perhaps take inspiration from other parents' research.

Nathalie Coqué, vice-president of the Alliance syndrome de Dra-

vet (Dravet syndrome Alliance) talks about her research in the area of adapted pedagogy, research she undertook for her son Achilles and for the members of this charity. How do we find the right method? Whose opinion should we trust? The charity "Neuf de cœur" (Nine of Hearts) can potentially provide us with some answers. There are also the methods that we [our members] are trying as you can read in the testimonial of Laurélyne's parents. She has made some progress with the Padovan method and there is a small section on "Equitherapy" as tested by Enrique and Idriss.

This newsletter only offers a little food for thought but in the words of Laurélyne's parents, it's perhaps in the relationship between the child, the parents and the therapist who works closely with them that we will find the secret of a re-education method that will prove fruitful.

Thank you for your support.

**Judette Lancrenon**  
 Association Director

PS: Thanks a lot to Laetitia, Maxime, Géraldine, Marie, Steve and everyone who worked on this newsletter and to everyone who contributed their own knowledge and experiences. We hope this collective work will benefit children and their families affected by FIRES.

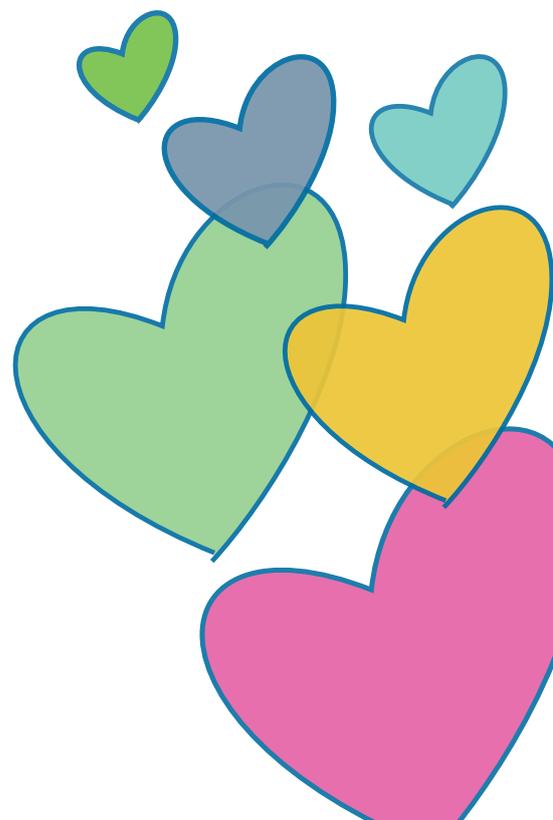
## ... Event ...

### 9<sup>th</sup> of June: First FIRES international day

The 9<sup>th</sup> of June 2013 saw the first International FIRES day. The online conference brought together 11 international medical experts as well as families affected by FIRES.



*Thank you to everyone who made the day a success.*



... Dossier ...

# Dealing with behaviors associated with refractory epilepsy

## FIRES and autistic behavior, what are the links?

By Lieven Lagae, MD PhD,  
Paediatric Neurology - Epilepsy,  
President of the European Paediatric  
Neurology Society,  
Editor-in-chief European Journal of  
Paediatric Neurology

The association between FIRES and autistic behavior remains interesting and a challenge to understand.

The key question is whether this autistic behavior seen in children with FIRES is very specific for this epilepsy syndrome. Indeed many early onset epilepsies are associated with autism. For instance, in tuberous sclero-

sis, children often present with infantile spasms in the first year of life and develop severe autism in the next years. It is believed that this might be associated with interference of the developing communicative networks in the brain at this vulnerable age. Autistic behavior is seen in many other refractory epilepsies, such as Lennox Gastaut and Dravet syndrome. So it seems that refractory epilepsy is indeed a risk factor for developing autistic traits. Now, FIRES is a special case, since most children with FIRES only start with their epilepsy after the age of 4-5 years. At that

age, it can be expected that normal communication and social interactions are already well developed. In this way the occurrence of autism in FIRES is somewhat surprising: is it due to the unexplained and not yet well understood inflammatory changes in FIRES, is it due to the specificities of the epilepsy (for instance more frontal lobe seizures), or is it again due to the fact that many FIRES children have refractory epilepsy? We do not know yet.

> Read the full article at  
[www.associationparatonnerre.org](http://www.associationparatonnerre.org)

## FIRES syndrome and speech therapy



By Lauriane  
Venin-Consol,  
speech therapist  
accompanying chil-  
dren with autism

**Autistic children are often epileptic and, sometimes, children affected by FIRES can develop autistic behaviour. Which tools and methods do you use with autistic children that could also be effective for children affected by FIRES?**

I will speak here about my experience with children affected by autism. Patients with other disorders won't have the same needs. I will only speak here about a few leads, because there are as many care projects as there are children, and a wide-range of methods.

For "challenging" behaviour, organising time and space is essential in the support of autistic children. This aims to help the child to plan, anticipate and organise their environment. Vertical visual charts presenting a series of activities during the day are often used. It could be a photo of fami-

liar places or a photo of someone. When a child has a lower level of distraction, the plan can be made with pictograms or sentences. Often, it is possible to Velcro the pictures, so when the activity is finished, the picture of the activity can be removed.

For children who speak just a little or not at all, I use signs from the Makaton method and some pictograms. The idea of this method is to sign the key words in a sentence while enunciating them.

This helps a child to visualise words which, without this method, are mixed with all other words (phenomenon known as "speech co-articulation"). This also naturally leads the speaker to slow down his speech. This method is then either an augmentative one (which allows the speech development) or a palliative one (in which case a child starts using sign language without making an association with the spoken word). Moreover, in most cases, the signs help to support the understanding of speech.

For other children, the PECS method

will be more useful. Its idea is to communicate by swapping pictures (photos, pictures, pictograms). Sometimes children prefer a method of communication using item swapping as it feels more real.

A child's motivation is key in our "small educative victories", experienced in session after session. I use lots of "reinforcers" specific to each child because they do not always have the same values as us. For instance, I can put a desired item in a child's third basket (a sensorial item, a desk-game that the child has spotted, some bubbles, a sweet...). The child then knows what he or she is working for.

Also, it is important to highlight the development of technologies that are more specific to children who cannot communicate with speaking: speech synthesisers, electronic communication tables, digital tablets... For instance, there are some reasonably priced, effective communication tools on the iPad, which has the added advantage of being light and easy to carry.

> Read the full article at  
[www.associationparatonnerre.org](http://www.associationparatonnerre.org)

## Educational tools for children presenting autistic disorders



**Nathalie Coqué is vice president of the Association "Alliance Syndrome de Dravet" (Dravet Syndrome Alliance).**

**Dravet syndrome is a rare and serious form of epilepsy** which affects children, with seizures appearing in their first year of life. It is a drug-resistant epilepsy which leads to behavioural and learning disorders ranging from minor to severe disorders. Nathalie explains here the different methods she has explored in order to help her son, Achille, in his learning process, and which could help children affected by similar disorder including speech and psychomotor delays, walking and fine motor skills, ataxia, behavioural disorders (hyperactivity/autism)...

Seeing that her child demonstrated disorders shared by autistic children, Nathalie approached autism associations, which helped her discover different stimulation and learning methods used for these children. As she followed her son's progress, she collected a number of resources to help Achille's communication and learning.

**Her first step was to help Achille's with his communication** (for more details see <http://www.alliancesyndromededravet.fr/comment-aider-nos-enfants-a-la-communication-et-au-langage/>). She first used the method called "Signe Avec Moi" ("Sign With Me": a sign language for infants). It starts with a few signs,

following the child's interests: if they want to indicate that they want more of something, or if they want to eat or drink, or have a biscuit etc... The child is able to sign as soon as he or she starts pointing what he or she wants. That's how Achille made his first sign, "more" after 7 months of his mum signing a few words for him. Then Achille was taken onboard by a speech therapist using "Makaton", he had 3 sessions a week.

**Makaton is a program to help communication and speech.** It is a mix of sign language (drawn for most part from LSF "French Sign Language"), pictograms which can be pointed at and speech. Signs and pictograms help for a visual representation of speech in order to improve understanding and facilitate locution. Its goal is not to be a substitution for verbalisation but quite the opposite it is an extra help to facilitate spoken communication.

**Today, Achille uses more than 30 signs.** For Nathalie, this really helped him to communicate despite his lack of speech; it also helped him to come out of himself. For Nathalie, signing is the first step towards language. She also uses pictograms. They are everywhere in the house: on the fridge, those for eating and drinking that Achille points to or brings to her when he is hungry or thirsty. In the bathroom, there are several images to remind the child of the different steps to follow to go to the toilet, wash his hands, or brush his teeth... Nathalie has created all these pictograms herself, starting with photos

taken in Achille's usual surroundings, then she carried on with drawings (A picture is worth a thousand words). The stylised symbols in Makaton will be for later, because many of them need the child to be able to interpret them.

In this way, it is possible to progressively introduce pictures adapted to the child's comprehension: photos with the child himself in the situation, drawings (in color or black and white), stylised pictograms, and then written words.

**For Nathalie, it doesn't matter what the method is, what is important is that the method fits the child, and fits what (s)he likes and knows best:** some have a very good auditory memory, other are more visual...

**A multi-sensory approach is always offered to the child, joining the picture to a sound, a texture, a sign...** In this way, Achille gets to know the first letter of his name touching the letter A in sand paper and every texture can be a support for learning: glitter glue, wool, Velcro... It is inspired by Maria Montessori's pedagogy.

**For behavioural disorders, we turn to ABA and/or Teacch...** An interesting method called ABCboum, which is not well-known in France, aids graphic learning and was created specifically for children with perception and motor difficulties. It is a Canadian method which associates basic lines with sounds and pictograms. Progressively, the child can practise writing letters.

### Nathalie's resources

#### BOOKS

- **Signe avec moi : la langue gestuelle des sourds à la portée de tous les bébés** (Sign with me: Sign language with sounds for infants) - Nathanaëlle Bouhier-Charles, Ed. Monica Companys. This book teaches how to sign simple words with the child.
- **Activités d'enseignement pour enfants autistes nouvelle présentation.** (Teaching activities for children with autism : A new presentation) Schopler et Lansing, Ed. Elsevier-Masson

- **Autisme et A.B.A.: une pédagogie du progrès.** (Autism and ABA: a progress pedagogy) R. Leaf, J. McEachin, Ed. Pearson

#### WEB

- **Le Blog d'Hector**, (Hector's blog): Written by the mum of Hector who is almost 5 and who has Down's syndrome, this blog is a reference point for every child who needs adapted learning methods. <http://hectorzblog.blogspot.fr/>
- **ABCboum** : <http://abcboum.net>

#### GAME

- **A picture paints a thousand words:** [www.lespictogrammes.com/boutique.php?product\\_uid=2](http://www.lespictogrammes.com/boutique.php?product_uid=2)

#### TRAINING

- **Epsilon at school** by Lydie Laurent, [www.epsilonecole.com/calendrier](http://www.epsilonecole.com/calendrier)
- **Learning and Schooling** [www.autisme-apprentissages.org](http://www.autisme-apprentissages.org)

**ALLIANCE SYNDROME DE DRAVET**  
[www.alliancesyndromededravet.fr](http://www.alliancesyndromededravet.fr)

... Dossier ...



## Association Neuf de Cœur

Support and inform children's families suffering from brain damage  
[www.9decoeur.org](http://www.9decoeur.org)

By **Florence Papin**,  
President of Neuf de Cœur

The therapies suggested by Neuf de Cœur are recognised methods which are practised either by a number of our members, or by those close to us, and which, of course, have been effective. Our budget doesn't allow us to finance all the therapies that are on offer and which are undoubtedly valid. In making our decisions we rely on our own knowledge but also medical advice if necessary. Furthermore we aim to exercise a great deal of care when making our choices.

In concrete terms, what a family can expect from Neuf de Cœur are suggestions regarding therapies, which, of course, complement the neurological treatments that are already being followed. Furthermore we provide information regarding the creation of an association for your child and offer assistance with administrative steps, as well as sharing information regarding the experiences of other families and the route they took. We are also able to listen to you at crucial moments of decision making. This is an overview of the help that we offer and we hope to offer a real support to families with the experience that we have gained in over 15 years of existence.

It is very tricky for us to specify exactly which re-education techniques would have a positive effect for children with FIRES, however, amongst others the Doman Institutes in Philadelphia have "masking" programmes which have had really encouraging results for children with epilepsy. Close to us, a young girl went from experiencing between 30 and 40 seizures a day to none. It has to be said that that each case is different and is subject to a number a different and neurological and physiological factors but this method was particularly beneficial.

> Read the full article at  
[www.associationparatonnerre.org](http://www.associationparatonnerre.org)

## NeuroOptimal, approved by Neuf de Cœur



With **Corinne Fournier**, founder of the Neuroker Institute.

In this interview Fournier acquaints us with neuro-

feedback and explains the scientific basis of the Neuroker Institute's NeuroOptimal method.

### In a few words, what is neurofeedback?

Neurofeedback is an approach which can enable the brain to reorganise itself in order to function better. Through electrodes placed on the scalp, the system analyses the brain's electrical activity, then sends this information back to the brain regarding its own functioning.

### How could this type of treatment help children living with FIRES?

As with many methods, it is only in repeated practice that we will be

able to measure the effects of a NeuroOptimal treatment for the individual child. I have never treated a client diagnosed with FIRES, however I have worked with a number of clients with severe epilepsy (with a diverse range of causes). Often neurofeedback reduces the frequency and the intensity of seizures. In several cases the medication dosage was reduced or even stopped. One young woman who used to have daily episodes hasn't had a single one for three or four years since she followed a neurofeedback treatment.

### What are the potential effects for problems linked to epilepsy including motor problems, speech problems, difficulty managing emotions and autism, which are often more disabling than the actual epilepsy?

There again only practice will tell. The changes we have seen previously have taken place in extremely diverse domains.

> Read the full article at  
[www.associationparatonnerre.org](http://www.associationparatonnerre.org)

## Equitherapy: horseriding as therapy

By **Karine Martin**, equitherapist

Equitherapy doesn't directly treat epilepsy, even if people affected by epilepsy usually have fewer seizures when they have contact with horses. However, equitherapy treats side effects and motor and cognitive sequels, offering an overall support for the child. Indeed, exercises with ponies focus on balance, lateralization, praxis disorders and fine motor skills. Ponies render the cognitive learning and the upholding of acquired skills easier. It is important to find the right equitherapist who knows how to adapt the therapy according to the problems and capacities of the child. Please be mindful that as equitherapy is not a regulated occupation yet, many people pretend to be an equitherapist without having the right skills and training.

If you are looking for a professional equitherapist, it is essential to seek

the advice of the 3 existing authorities in France: "La Fédération Nationale de Thérapie avec le Cheval" (National Federation of Therapy with Horses), "L'Institut de formation en équithérapie" (The equitherapy training institute) and "la Société Française d'Equithérapie" (French society of equitherapy). An equitherapist must first be a health professional who has had a complementary training in equitherapy, and who has then graduated and has signed the ethical and deontological professional chart.

<http://sfequitherapie.free.fr>



## Laurelyne's testimony



Laurelyne was struck by FIRES syndrome in the summer of 2011. When she left hospital in October, she was unable to eat using her mouth, she was moving but not walking and she wasn't talking any more. As of today, Laurelyne has regained many functions. Here is Marc and Sandrine, Laurelyne's parents', view, on her journey since she left hospital a year and a half ago and her progress.

We had been in the centre for eight months when Laurelyne came home for good in July 2012. We felt that she had seen all of the benefits that classic re-education could have brought her.

We then turned to Padovan method which we had heard about. It seemed to be the best for Laurelyne because it allowed us to reduce the number of people who needed to interact with her and it appeared very promising. Luckily we found someone really good who wasn't too far from us: a speech-therapist who managed to take Laurelyne on board on an intensive basis, as some of the children she was working with were on holiday. We started straight away with 4 to 5 sessions a week. **Progress was rather fast. For us, there is an obvious link between the Padovan method and her progress:** in terms of alert-

ness, attitude, it is in really small subtle things. Straight away, we were noting progress; she was doing the exercises more attentively, differently. She tired less easily, and then she started to swallow her saliva, she improved the muscle tone in her hand, and her gripping skills.

**At the end of October we saw an acupuncturist** who made a first assessment of Laurelyne. She had a slightly spiritual approach, mostly based on feelings. You had to be open to this new way of seeing the suffering linked to Laurelyne's seizures, which were painful. Every time, there were tears, her body would go stiff, sometimes up to the point where she couldn't stay in the pram or couldn't walk.

**We also did osteopathy sessions. And at the same time, we raised the level of one the medications she was taking,** while we were decreasing another one.

We reached the maximum dose on the 20<sup>th</sup> of November.

Early December, Laurelyne started having fewer seizures, then none at all. We felt that the drug but furthermore the alternative therapies in particular enabled the seizures to decrease thanks to her feeling better in her body, which stopped this vicious circle of seizures.

From this, the progress which up to then had been so subtle, and so hard to evaluate, became objective and incontestable: in terms of walking, she was able to lift her leg to climb a step, climb on her bed, use her right hand and she became right-handed again... She follows us with her eyes,

her gaze is deeper, larger, and since last week she calls (Laurelyne makes "singing sighs").

**We added some physio sessions** a month and a half ago, we think it helped her gain muscle tone and especially her lung capacity increased. The main improvements recently have been smiles, facial expressions, and she started eating again in January! We took things really slowly. We started with 20 grams a day, 3 spoons of pureed fruit and it took her an extremely long time to eat them. Today, she can show us if she doesn't want any, she turns her head. We didn't think we would ever see that again, but now she eats a whole meal in about half an hour! It is hard because even if we were following Laurelyne in her progress, we didn't set out with a plan, we just followed our instinct.

The most important thing is to be surrounded by people you trust. If we trust the therapist, it usually goes well with Laurelyne, and in return, if it goes well with Laurelyne, we will share more and it is by sharing that we progress. Laurelyne's therapists trust the knowledge we have of our child and always ask us lots of questions.

**"The most important thing is to be surrounded by people you trust."**

If parents don't feel this way, then I think there is no point because indeed, we are the ones

who know our children the best even if we had to get to know them again following the onset of the disease. The relationship with the therapists is very important.

In everyday life, we sometimes share even more things with them than with our close families who we sometimes want to protect. Hence of all the people close to us, it might be the therapist who has the best idea of what we are going through.

> Read the full article at [www.associationparatonnerre.org](http://www.associationparatonnerre.org)