



L'ARMC

l'Aide à la Recherche des Maladies du Cerveau
"la Jeanne Hamon-Frostin"

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"J'ai parrainé l'ARMC
parce que c'est une petite
association qui défend une
grande cause."

Loïck PEYRON,
10 avril 2014

"Toute douleur
qui n'aide personne
est absurde"

André MALRAUX

"L'espoir est
toujours à portée de
Cœurs."

Yves DUTEIL



"ARMC, the association that supports life"

Pleucadeuc 16 April 2021

How did the ARMC come about?

In the document that she wrote a few months before her death, my wife, Jeanne Hamon-Frostin, left us this message *"it has been three years since I had a new companion, I did not invite her. She is a part of me. She lives in me. We live in harmony with each other and I know that she will win one day, but no matter what, we have to postpone the deadline... Since 2009, I no longer eat, I no longer drink, worse I can't speak any more, but I'm not unhappy and I am happy to be alive."* This three-page essay about *"her new companion"* – as she called her illness – drew both touching and moving responses from those who read it.

On the ARMC website – which has just been updated and we invite you to visit it – on the home page you will find – Jeanne's full message from *"Origin of the ARMC: my new companion"*.

"People can be overwhelmed when the disease is diagnosed and experienced." Jeanne's testimony is that of many patients with ALS. Following her death at Christmas 2011 we set up this charity with the sole purpose of continuing the fight against this terrible neurodegenerative disease, in order to help others.

The objective of the ARMC is twofold

- 1) Help for patients, personally, professionally and financially
- 2) Contributing to the funding of medical research.

Since January 2012, we have been helping to fund medical research and our patients, because we believe that the unequal fight we waged with Jeanne during the four years of her illness is still worthwhile, to help others.

I regularly visit families who ask for me in my own area of the Morbihan, and I become a caregiver with them. Patients and their families are often distraught by the lack of support and information. They have many questions about what happens and when, as they will have vital choices to make. ***From my experience, over four years of caring for my wife who suffered from the bulbar form, I am able to assess the stage of the disease and work out its progression.*** I believe that the most important thing during my visits to patients and their families is, in addition to the advice I can give, to allow the patient to confide in someone they can trust. ***In fact the most important cog in the treatment of this disease is the GP*** because they co-ordinate between specialist colleagues in order to bring the patient ***both comfort and reassurance.*** ***Unfortunately, there is nothing more that we can do for the ALS patient.***

It is important for us to add here that we are available to patients and their families in order to advise, guide and / or simply listen to those who need it. We are the intermediary between the healthcare professional and patients with ALS – without replacing the former – simply caregivers and helpers who have become experts in ALS. Specialists don't always have the time to listen, but we can offer support. We do not forget either the many patients who find themselves in significant distress after having tried everything because contrary to what some specialists say, ***there is always something that can be done to remain hopeful and optimistic and to exchange views with them and by discussion we can find out what will help.***

When an ALS diagnosis is currently made in France we are ***"in a race against time, against death that can happen any time from a few months to a few years"***. The researchers of the renowned team of Séverine BOILLEE at the ICM sent us a double-sided page that they wrote at our request to help us with our presentations to students and the educational community: ***"The work of a researcher is not just a job. You never do it for the money, but a lot of your time is spent researching so that you can carry out experiments using advanced techniques which can be very expensive"***.

Everyone will readily understand that by helping the researchers it gives them greater opportunities to invest time to search for new therapies that hopefully will succeed in slowing the progression of the disease – even if it fails to cure it.

At the same time, Covid 19 challenges the whole world and we must adapt to life with this tenacious virus which is going to be around for much longer than we had imagined and which makes our leaders say ***"we will need to learn how to get used to living with it"***.

This is why, if we want researchers to get results, we have to find a way to support them and help them find answers. ***Therefore, we must study and learn from every opportunity that arises so that we can continue to give priority to helping the medical research which is so desperately needed.***

It is this imperative that constantly drives me to ask for help and support, according to the motto of our Honorary President Joseph BRIEND who from up there now continues to watch over us ***"Help yourself and heaven will help you."***

The Institute for the brain wrote in July 2012, ***"Today one in eight people is affected by diseases which are characterised by lesional damage to the brain, spinal cord, peripheral nerves or muscles. These are chronic, disabling illnesses involving significant medico-social care."***

What is the ARMC doing 10 years later?

"The ARMC is a small association that supports a great cause", that was the answer that Loïck Peyron gave in mid-April 2014 to the journalist who asked him the question ***"Why did you sponsor the ARMC?"*** – ***I have not found a better definition since.***

Today, ARMC is in partnership with **Morbihan CPAM**, the **Mobile Team** and the multidisciplinary ALS unit at the **Kerpape Center**.

We have made a commitment to support **INSERM**, that we renew annually at the beginning of each year.

One research project that we have been supporting since Christmas 2015 with Séverine Boillée's team is called: ***"Causes of ALS and mechanisms of motor neural degeneration"***.

We run presentations for students and educational communities to explain the facts of the ARMC's annual project.

We have a stall at Christmas markets and / or Vannes market at Christmas and Easter.

July 14th is a day of great solidarity in Pleucadeuc, which is now called ***"the Day of Smiles"***.

To date we have given **€ 200,792.48 in donations** to medical research and various aid for ALS patients, including the multidisciplinary ALS unit at the Kerpape center.

In regard to our area of special interest, **the ARMC is above all a small association** which, in the midst of a health pandemic, continues unabated to ***primarily aid medical research for a neurodegenerative disease***. At the same time, the eminent team of Séverine BOILLEE at the ICM have said to us for several years that ***"the day we make a major discovery, it will have repercussions on Alzheimer's disease, Multiple Sclerosis and Parkinson's disease"*** all of which are currently without a cure.

Where are we 10 years later?

Despite the constant struggle over the last 10 years, it is clear - ***regardless of the effects of statements that come back to us at regular intervals from around the world*** - that there is still nothing on the horizon and only Rilutek / Riluzole remains available. Exorbitantly expensive – no-one is interested in finding another drug – ***because it is not financially viable*** as this is a rare disease which nevertheless loses as many patients as there are new cases each year.

We are led to believe that there is only one drug, still prescribed today, but it only increases life expectancy by a few weeks. Scientifically the premise is weak, there must be something else out there.

Morally speaking, to date the only drug worthy of the name that exists on the market for people with ALS is: the support of friends and relatives, their GP, a good physiotherapist and the etiopath, because Rilutek is not the solution.

A word from Mikael MOAZAN, President of ARMOR ALS in Saint Brieuc

The ongoing struggle gives us hope while reinforcing that insurmountable obstacles exist. The fight against disease, in all its forms, is also accompanied by a permanent fight against these obstacles. Do not ask researchers to make promises to us. *Let's help them find answers. And let them innovate in that search.* As far as we are concerned, it is our job to *"take care"*, that is, not in "the relationship to", but in "a relationship between". *Everyone here knows that their own life experience changes when they come into contact with each other.*

To help is above all to share.

The ARMC is helping research on all fronts!

ARMC's annual donations are now directed to the research project that we officially support at the ICM, but also to the mobile team at the Kerpape center. Dr Delphine Bohl, who comes regularly to the events we offer here explains how they use donations given for research, of course, but not just for research.

Like any academic research team, Dr. Boillée's team at the ICM is made up of researchers (4 researchers including Doctors Millecamps, Lobsiger and myself), technicians and students. Each of us has specific expertise and our job is to read research articles, interact with the scientific community, come up with new hypotheses, and then seek to validate our ideas in concrete terms. The next stage is the technicians and the students who carry out the experiments. While we have permanent positions, like the majority of researchers in France, this is not the case for students whether they are preparing their thesis (Bac + 5) or in post-doctoral internship (Bac + 8). Only students who are working on their thesis can benefit from a 3-year endowment from the university. Competition is strong and not all students get this help. It is true to say that there is not enough public funding going towards educating and supporting students today. Even with financial aid, there is far from enough to carry out cutting-edge research as new technologies are expensive but necessary to replace outmoded methods. Money is the crux of the matter. As researchers we have to apply for funding from different organizations to pay for students and experiments. This exercise should not be considered a waste of time because it allows us to bring forward new ideas for review by expert colleagues. The concern is that the competition is great and funding is never guaranteed. This is why we have to keep on applying and this is where we are wasting time. In this context, the help of the ARMC is invaluable for the team because here there is no selection process, but a unique confidence given to us. For us, this help from the ARMC is priceless because it gives us the freedom to seek avenues and solutions the sooner to help patients with Charcot's disease. We are infinitely grateful to the ARMC for the support that they have given for 6 years now. This is how the ARMC helps research on all fronts, saves time, and also helps students from the team to finish their doctorates and thus obtain their Research Doctor degree, the highest university degree in France. The new doctors in the team, who have thus made concrete progress in the research projects, have also acquired expertise which enables them in turn to propose new projects.

Dr Delphine BOHL

I would like to warmly thank Clément, a founding member of the ARMC and of the Board of Directors for allowing us to present the ARMC here. I would like to thank all of you here who join in the never-ending struggle of the ARMC. I am not working for my generation, for mine it is too late, but for that of my children who will one day experience the therapeutic advances that we dream of today.

***"It is not known whether a fight leads to victory,
but a big part of success is found in commitment which is already a form of success."***

Claude Hamon ILEPS 1965 / Secretary, Founder of ARMC
<https://armc-pleucadeuc.com>