2002-2003 NEWSLETTERS

2002 CADASIL Newsletters

The unofficial CADASIL newsletter Issue VIIII - June 2002

CADASIL - Cerebral Autosomal dominant arteriopathy with sub cortical infarctions and Leukoencephalopathy recently identified, CADASIL is a diffuse disease of small arteries predominating in the brain. It starts during mid adulthood and is characterized by recurrent ischemic events (transient or permanent), attacks of migraine with aura, severe mood disorders, and sub cortical dementia and, at MRI, and a white spread Leukoencephalopathy.

How did this newsletter began:

I researched through the Internet in February 1997 and looked up excessive white matter, anything from the results of MRI and CT scans. I contacted Steve's Doctor and received copies of his files. I placed the files on a word-perfect file and sent more than 200 E-mails out with my husbands' history and asked for help. I learned that sometimes you must be your own case manager to learn anything. I had and have hoped for my husband and my family. I told my husband that each time I searched on the Internet and when I press the send button on an e-mail, that one day there will be a cure for this nightmare. I developed a web site for CADASIL in hopes I could help others and find out more about this disease. Well, the response has been fantastic. This went from helping others to a support group link. No words could express the amount of thanks to everyone who has contributed to the web site and newsletters. Please remember "TOGETHER WE DO HAVE HOPE."

Information on CADASIL from France -

I am a member of the ACF France association that gathers persons suffering from CADASIL and their families with doctors belonging to the teams that identified the gene involved in the disease and still working in the field of CADASIL research. At the end of 2001, we had a meeting with the French Researchers. I've tried to translate in English the minutes of the medical discussion we had with them. I hope it will give you some encouraging information. From C
Thanks for the information!

ACF-France Cerebral Familial Arteriolopathies Association) Registered office: Hospital Lariboisière - PARIS

MEDICAL DISCUSSION WITH THE FRENCH RESEARCH TEAM DURING ACF'S GENERAL ASSEMBLY ON NOV 17TH 2001

1. What can be done when the first symptoms appear? Prof E. TOURNIER-LASSERVE: as a first step, you should visit your family general practitioner who will determine if he has to address you to your neurologist, if necessary. Some neurological symptoms are not compulsory linked to CADASIL In the case of a cerebral stroke, an MRI exam has to be performed.

2. What do you think about thrombosis's and anticoagulant treatments? Prof. E. TOURNIER-LASSERVE: They are not appropriate as they induce the risk of a cerebral blood hemorrhage. The stroke itself can already be accompanied by very little bleedings. Prof. M.G. BOUSSER: there is no emergency treatment that can be prescribed immediately after a stroke. You also have to remember that CADASIL is not the only source of neurological symptoms.

3. What about arteriography? Dr. H. CHABRIAT: in an emergency, this exam is likely to be performed by the hospital. But there are some risks, as it requires an injection of iodine in the artery. It is not advisable.

4. People having the CADASIL disease should always have a card in their wallet with indications on their illness and the treatments and exams that have to be avoided. Dr H. CHABRIAT: vasoconstriction medicines (issued from rye ergot or from Tripoptan) are also dangerous. Products aiming at unblocking blood vessels are inadequate as they increase the risk of a hemorrhage. Prof. E. TOURNIER-LASSERVE: keep in mind that they are other diseases that affect small blood vessels. Having neurological signs doesn't compulsorily mean that you suffer from CADASIL. The diagnosis of this illness requires a whole process of analysis.

5. Is it forbidden to take Aspirin or Plavix?
Prof. M.G. BOUSSER: No. A 1978 study has shown that aspirin can decrease by 25% the risk of a second stroke after a TIA (transitory ischemic attack: stroke provoked by a jam in arteries, in opposition with strokes generated by blood punctures). Aspirin and anti-platelet medicines provide some benefit. Some research works in that field have been conducted in cases of other diseases with thickening of blood vessel walls, but not yet on CADASIL patients. As for anticoagulant pharmaceutical products, they increase the risk of a hemorrhage. A recent American study shows that they are not more efficient than aspirin. Strokes caused by CADASIL are more frequently ischemic than hemorrhagic.

Prof. E.TOURNIER-LASSERVE: The first step in our Research activity was the identification of the gene implied in the disease. We then worked on the protein produced by the muted gene. This gave as consequently some information for diagnosis, knowledge on the mechanisms of the disease and orientations for defining the characteristics of the adequate treatments we have to look for. A

third step is to understand the role plaid by this protein when there is no mutation in the gene. We have produced laboratory animals having the genetic mutation in order to study when and how the brain lesions appear, and how they progress while generating symptoms. We also cultivate cells in tubes in order to get quicker tools.

6. The Notch 3 gene plays a role in muscular cells where it determines the vessels' constriction. In Dr. JOUTEL's laboratory, an animal model has been obtained (transgenic mice): it has the Notch 3 gene mutation that was identified in several families. At an age of about fifteen months, these mice had the same brain lesions as in the human form of the disease. The purposes of the present studies concern the following questions: when do these lesions appear? How do they develop? What are their consequences? Which products can slow down their evolution and impact? We will try to get some mice that will present the disease earlier to accelerate our observations. At the present time, the most important is to discover the normal role of the protein and Researchers have now some serious hypothesis. We also have other Research activities on other cerebral arteriopathy diseases that have similarities with CADASIL. The affected families could join the ACF France association.

7. Could genetic therapy be considered?
Prof. E. TOURNIER-LASSERVE: there is little chance that we can consider developing genetic therapy. The elaboration of pharmaceutical solutions will much more easily be achieved. If we find a medical cure, people identified with having the muted gene could get it on a preventive basis before onset of the disease. This would be a sufficient protection. We now have serious hypotheses for finding pre-symptomatic treatments.

8. Do you advise some particular life habits?
Prof. M-G. BOUSSER: it is recommended to avoid smoking, drink alcohol in reasonable quantities (however, two glasses of wine daily for a man, and one glass for a woman, can even have a protecting role) and have regular physical activities.

9. Do you think it is not advisable to take contraceptive pills? Prof. M-G. BOUSSER: It is known they have a negative impact on blood circulation. But, pills having a very low concentration are not dangerous if you don't smoke and do not suffer from diabetes. If the woman has CADASIL, it is not unreasonable to counsel avoiding taking contraceptive pills, but we don't have a definite position on the matter. Dr. H. CHABRIAT: there is no thrombosis - like symptoms in the illness. Prof. M-G. BOUSSER: Pills without estrogen (progestative pills) have never been identified for increasing the vascular risks.

9. What can be the consequences of menopause treatments? Prof. M-G. BOUSSER : it is difficult to determine whether hormones can have a protecting role against cerebral strokes. There has been a study on substitutive

hormonotherapy. But its results were not significant enough as the panel of women concerned was not representative of all social contexts. Before the age of fifty, women have less strokes, in average, than men: there are 50% less myocardium or cerebral infarcts, but no serious research has measured the impact of menopause on these accidents (it should be conducted on 10 000 women for getting serious results). A positive role of menopause treatments against a second accident has been observed on women who have already suffered from a heart attack. We cannot formally say that hormonotherapy. has more pros than cons for a woman having CADASIL. The treatment's choice has to be established on other criterions: it is not advised in families where there are many cases of cancers but is counseled for persons who are depressed or suffer from hot flushes.

10. What do you think about menopause treatment with plants? Prof. M-G.BOUSSER: There is no significant study and no serious results in the field of hormonotherapy. using plants.

11. Does pregnancy introduce some risks? And it is possible to identify CADASIL on children? Prof. M-G. BOUSSER: There is no increase in the risk of a stroke during pregnancy. But the month following the birth is more risky with a higher probability of phlebitis and strokes. But pregnancy doesn't favor the apparition of CADASIL. Prof. E. TOURNIER-LASSERVE: The genetic mutation exists right from the conception. At the very stage of an embryo, the presence of the muted gene could be identified. But it raises many questions: is it good to know it, and when, whereas there is still no treatment? The research work on animals is important to better know the impact of pregnancy. Prof. M-G. BOUSSER: our opinions are based on similar illnesses, by analogy, but there never has been any particular study on pregnancy and CADASIL.

12. Do you have in the Lariboisière hospital information on all persons identified in France or only on patients for whom doctor H. CHABRIAT cares? Dr. H. CHABRIAT: we do not have a centralized follow-up of all French patients. We have presented a project aiming at subjecting all patients all over France to the same cerebral MRI exams and cares. But we didn't get the necessary subsidies. We will request some funds in the coming months from other sources and we are looking for financial means for larger scale studies. Prof. E. TOURNIER-LASSERVE: associations have a major role to play for diffusing the knowledge on the illness and get some funds. Prof. H. CHABRIAT: as far as follow-up surveys are concerned, we collaborate with the German Research team in Munich, which has significant financial means. We would like to develop the same follow-up work in both countries.

13. How many CADASIL patients have been identified? Prof. H. CHABRIAT: about 50 to 60 in the Paris area. On the whole French territory, we do not have precise figures, and some individuals have probably not been diagnosed. There are neither any statistics on a worldwide scale. Prof. E. TOURNIER-LASSERVE:

in our genetic laboratory, we receive yearly about 200 to 300 blood samples, among which only about 20% are diagnosed with a CADASIL mutation in the Notch3 gene. A member: In addition to a web site, it would be useful to issue a scientific bulletin for medical staff with information on the progress of Research works. Prof. M-G. BOUSSER: We have major difficulties in obtaining funds for Research. In Germany, there are 5 times more doctors than in France. We are not numerous enough.

14. Does the German team get interesting results? Dr. H. CHABRIAT: they have interesting results. Their evaluation method of the disease is based on a gravity scale of the handicap and its evolution.

15. In France, do you have some new results?
Dr. H. CHABRIAT: if we want to organize a therapeutically test en France, we have to choose some evaluation criteria. Frequency of strokes? Migraines? The more visible and logical sign would be the handicap. But for getting significant results, this measure would require the follow-up of one thousand patients during 2 or 3 years: it would be too long and it is also impossible to identify so many patients and to have enough money to conduct this study. We have considered another criterion: MRI examination of water movements within is the brain (diffusion imagery). We know that the water mobility increases when the axons (prolongation of nervous cells in the brain) and myelin sheathes are damaged as a consequence of the lack in blood circulation within the brain's white matter.

During one year, we have performed a study on 25 patients in the Orsay hospital, using the diffusion MRI technique.14 of them have undergone a second examination and 7 had three. Even when these persons had no new symptoms and no stroke over a 34 months period, we could observe a modification in the water mobility curve, at each time they had the MRI examination. This technique enables us therefore to measure the modifications within the brain before they generate any aggravation in symptoms. In order to adjust this method and be able to use it for measuring the results of some therapeutically tests, it would be necessary to perform a test on a sample of only 200 persons, among which the half would be affected by CADASIL.

We have submitted our project to the French branch of a major international laboratory but the funds have been refused to us. Our project concerned a test with existing neuro-protecting medicines derived from statines (products used against cholesterol): they could limit the consequences of strokes and protect the brain by slowing the disease's evolution. The cost of this study is evaluated to 5 to 10 millions of euros. Prof. M-G. BOUSSER: we negotiated by insisting on the fact
that 30% of strokes are related to illnesses affecting small brain arteries, not only to CADASIL, which could open a broad market for pharmaceutical industries. We will go on presenting our project to other companies. Dr. H. CHABRIAT: Doctor VAHEDI will perform a study on the vascular reactivity with the use of echo-

Doppler measures. 40 patients and 20 control subjects will be appealed to in the first months of 2002. Theses exams require a whole day: MRI exam, neuropsychological examination and echo-Doppler. Prof. M-G. BOUSSER: our aim with the first tests of treatments is to determine if we can slow down the process and even to check if a reversion, possibly only a partial one, is feasible.

16. A psychological help is necessary for ill persons and their circle. Prof. M-G. BOUSSER: it is important to give information and that all Para-medical professions are implied in helping: psychologists, physiotherapists and speech therapists.

17. What do you think about narcotics?
Prof. M-G. BOUSSER: this is a major source of stroke in young populations. All drugs are of course inadvisable.

Information on the Website:

On the Website @ http://home.earthlink.net/~cadasil/

I have added a couple of things. How to file disability with Social Security. You see my husband, Steve at 45 years old cannot work anymore and we are going through this now. A wonderful person wrote on the e groups explaining how to do it and I revised it and put it on the Website.

I am still looking to go public with the disease here in the USA but no one will listen. This will not stop as I feel I need to go public with CADASIL.

We went to Houston, Texas a couple of weeks ago to check with the director of stroke. He took blood work for Steve's sticky blood symptom.

Steve has short-term memory loss now. He walks with a cane.

I wish to thank all the Doctors and Professor's, Doctors in France who might have helped us clarify some information on CADASIL.

This is letter, which my daughter wrote: My name is Noelle and I am in the eighth grade and I live in Texas. My dad has CADASIL this illness has effected everyone one in my family in their own different ways. I know this illness has affected you in your own personal but what I've learned is that all the pain and stress will make you a stronger person for the future. Noelle

Remember together we do have hope!
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Please print this newsletter out and pass on to your doctor or anyone who will listen. The more we education the public the more we have hope for a cure.

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YOU ARE NOT ALONE

2003 CADASIL NEWLETTER

The unofficial CADASIL newsletter Issue # 10 – August 2003

CADASIL - Cerebral autosomal dominant arteriopathy with sub cortical infarctions and leukoencephalopathy recently identified, CADASIL is a diffuse disease of small arteries predominating in the brain. CADASIL is characterized by recurrent ischemic events (transient or permanent), attacks of migraine with aura, severe mood disorders, and sub cortical dementia and, at MRI, and a white spread leukoencephalopathy. The Website is located at: http://www.home.earthlink.net/~cadasil/index.htm another person who is supportive of CADASIL has established another Website at http://www23.brinkster.com/cadasil2/cadasilhome

How did this newsletter began: After watching the movie Lorenzo's Oil I was inspired get on the Internet in February 1997 and looked up excessive white matter, anything from the results of MRI and CT scans. No Doctors could tell me what my husband had. I went to Steve's Doctor and got copies of his files. I typed them out and copied them to a word-perfect file. I sent more than 300 E-mails out with my husbands' history and asked for help. I learned that sometimes you must be your own case manager to learn anything. I have hope for my husband and my family. I told my husband that each time I get on the computer and when I press the send button on E-mail, that one day the hope is to find a cure for this nightmare. I developed a web site for CADASIL in hopes I could help others and find out more about this disease. Well, the response has been fantastic. This went from helping others to a support group link. No words could express the amount of thanks to everyone who has contributed to the web site and newsletters. Please remember "TOGETHER WE DO HAVE HOPE."

This is one description of many concerning CADASIL http://www.cafamily.org.uk/Direct/e10.html CADASIL is characterized by recurrent stroke most commonly first occurring in the 30's to 50's although it is now known that the disease can be very variable and in some people may not present until their 60's. A few individuals identified with CADASIL have remained well in there 70's. The type of stroke affecting people with CADASIL are lacunar strokes (literally meaning a small lake or hole in the brain). As these strokes are small, they tend to be fairly mild and individuals often recover well. The most common type of stroke is weakness affecting one side of the body. If recurrent strokes occur, this can lead to persistent disability, which is most usually arm or leg weakness, or slurring of the speech. Individuals with CADASIL can suffer from anxiety or depression. Depression is very frequent after any stroke and usually improves with time and treatment if necessary.

However, occasionally, depression may occur before any other symptoms of CADASIL. Rarely, seizures (epilepsy) occur as part of CADASIL. Over time, as the disease progresses, memory problems may occur and if these become severe, they are likely to occur in the 50's or 60's. Migraine is another common feature of the disease. This most commonly starts in the 20's but the onset is variable. Usually these are 'complex' migraines. This means that in addition to the headache there are short-lived neurological symptoms, most commonly, some disturbance of vision or numbness down one side of the body or speech disturbance. It is known that CADASIL results from an abnormality in one very small part of the notch 3 gene. It is thought that the protein produced by the notch 3 genes is responsible for communication between cells within the body, although much work is still required to confirm this.

As yet, it is not known why the abnormalities in the notch 3 gene in individuals with CADASIL result in the disease.

Further research will be needed to understand the disease mechanism. Although this is not fully understood it is known that patients with CADASIL suffer from progressive damage within small blood vessels. This is likely to lead to both reduced blood flow and an inability of the blood vessels to regulate blood flow. Although abnormalities in blood vessels can be found throughout the body, they appear to be most severe in the brain, and only produce problems noticed by the person with CADASIL within the brain. It is believed that the abnormalities within the brain result in reduced blood flow to certain parts of the brain.

Youngest Person with CADASIL A 14 year old has been having the severe headaches for about 3 years now and she has had 4 strokes and just got tested and has CADASIL. The research I have read on CADASIL stated onset mid adulthood.

This shakes up my whole world, as my comfort zone was that my two daughters who are 15 years old and 19 year of age could lead a normal life until mid adulthood. We just had a granddaughter who has made a meaning in our life.

Steve's progress Steve is now on permanent disability. He lives everyday with pain and the right side by his arm the muscles are so weak. About three years ago he had neuro psychology testing as a baseline and now he will have to go through it again. His short-term memory loss is very bad. His medicines are Topamax, Asprin, Celexa, Vitamin B, Zocor, Meprozine; He is also on blood thinner due to sticky blood syndrome and Avandia, Metformin for Diabetics. He was on Depakote for a long time but Topamax is newer drug with fewer side effects and seems to help Steve with his symptoms. He really thinks it helps a lot and I have seen articles stating that Topamax can reduce the risk of migraines. Steve cannot be under any stress at all or it brings out an attack and he is in bed or so weak.

Other stories and e-mails (I believe instead of myself going on about Steve and how we cope the e-mails from the e-mail support group which will help all us understand CADASIL and how we all cope with it) this list is also for doctors who have shown an interest and other To sign up, simply go to: http://www.egroups.com/subscribe/CADASIL

E-Mail #1 I was scared to death, because all the very very bad news I read!! I thought: Oh no, I am really dying!!! And then an other day I read something else, and I thought: oh well that person is still okay after so many years! I learned with time, that every person is different! My doctor told me that there

too early, but put it on the back burner. They can help you with their stories and how they deal with the same fears and difficulties. Do not be afraid to ask any questions, and no email is too long for those who know your fears.

E-Mail # 11 There are not in fact any more people getting CADASIL than there ever have been. The growing numbers come from the fact that more people, both affected and medical, are becoming aware of it. This is not sad, but a wonderful development. Instead of being battered around by wrong diagnoses and inappropriate treatments, people now understand what they are really dealing with. While CADASIL is not good news, for those affected, especially family and caregivers, it is immensely better to know what the real problem is, instead of futilely chasing down wrong roads.

We have a group here that collectively probably has more knowledge, experience, insight and compassion than any medical person or group in the world. The new people being welcomed here have finally found some sense of confidence that there is a definite explanation for what they have been trying to cope with. They are finding others who are dealing with the same things, and the group comprises a tremendous variety of experiences, current situations, and ways of dealing with CADASIL [including medications, research, venting to the group, and social and spiritual growth].

E-Mail # 12 I APPRECIATE ALL YOUR HELP! Thanks for this website and all this info. Occasionally I take a break form it as I struggle with depression. MY info from the lab state 30% of the people with CADASIL will have psychiatric problems; I never had a tendency to get depressed until these past three years not knowing what was wrong. This isn't an easy diagnosis to live with but I find comfort in knowing what I'm dealing with and Yes, I'm not alone.

E-Mail # 13 I felt numb in my hand, went up to my arm and then to my face! After a day or so I could not talk anymore, well not probably anyway! Doctor came and she said that I had flu!! A few days later my mum took me to a neurologist and finally he said that I had a stroke. And they found out after a few test that I have cadasil! I am 35 and I know it is hard to deal with. But remember you are not alone

E-Mail # 14 Of course, after several hours they reassured us everything was ok. The next day she went to her MD because everything was the same. On Friday, she had the tingling and a throbbing in her neck. Although our MD reassured us that it wasn't a stroke, she insisted she have a catscan.

E-Mail #15 The Catscan showed something and she was immediately taken for a MRI. Me - I wasn't even there for the first test because the doc said everything was ok. I showed up as the MRI was performed. I'm sure I will have to deal with that decision and my wife knows that I will be at EVERY doctor's appointment from now on.

The person who read the MRI said CADASIL. My doctor and the neurologist were clueless and had to look it up. I had to call my father in law to get any information on his wife. They had had the genetic testing. She had it, but we did not know. Her grandmother had strokes and her great grandmother had had strokes, but nobody knew why back then. My wife is devastated as we have watched her mother turn from a teacher into someone in a wheelchair. Her mother had her first stroke about 20 years ago. Before I was accepted to this site, I read various posts and had found the name of Doctor Lynch. What a godsend - I found an e-mail address and he answered me! I talked to him today and he has given me the name of somebody in my area to talk to.

Thank you again for this site. I consider myself fortunate at this point because this is my wife's only problem at this point. The MRI shows that she has had several TIAs beginning in her 30s. At this point in time, we know there will be more. I have already learned why you told me to be my wife's case manager as I have already found connections that my wife's doctor probably would never have found. To one and all, you MUST be their advocate as well. It was my wife's insistence that led to her first test.

Good News: The National Organization for Rare Disorders (NORD) has put the website for CADASIL on their Organizational Database to find a support group or other source of help with CADASIL.

United Leukodystrophy Foundation (ULF) 2304 Highland Drive * Sycamore, Illinois USA 60178 Phone: (800) 728-5483 FAX: (815) 895-2432 The web site address is http://www.ulf.org/. If you would like more information on ULF, you can contact them. They send newsletters out every quarter and deal with all the Leukodystrophy diseases.

The leukodystrophies are genetically determined progressive disorders that affect the brain, spinal cord and peripheral nerves. The term Leukodystrophy derives from the Greek words "lueko" meaning white and referring to the white matter of the nervous system. "Dystrophy" means imperfect growth or development. If you know more, please let me know. Usually when CADASIL patients are first evaluated the doctor's rule out M/S or another dystrophy, as CADASIL is still a new disease.

This information came from the http://www.ulf.org/ulf/intro/#Inf13 (CADASIL) is a frequently overlooked cause of leukoencephalopathy leading to stroke and dementia in early middle age. Radiological signs of this cerebral non-atherosclerotic, non-amyloid angiopathy may be present from childhood at a presymptomatic stage of the disease so that it can come to the attention of the child

neurologist. This disorder was first reported by Sourander and Walinder in 1977 in a Swedish family with a hereditary form of multi-infarct dementia. The same year, Stevens, Hewlett, and Brownell reported on a similar disorder under the title: "chronic familial vascular encephalopathy."

Migraine with or without aura begins in the fourth decade. Within the next decade, transient ischemic attacks and small strokes are evident. Mood disturbances and dementia follow, usually before age 60. Chabriat et al, in their review of 45 affected patients in 7 families (Lancet 1995;346:934) found that symptoms began at a mean age of 45.1 years and death resulted an average of 21.5 years later. Epilepsy has been described in a few cases.

The brain MRI demonstrates symmetrical confluent high signal areas on proton density and T2-weighted images throughout deep white matter of both cerebral hemispheres. There are also multiple focal low-signal areas on T1-weighted images indicating cystic or necrotic lesions within the white matter and separate discrete punctuate lesions up to 2 cm throughout the brainstem, thalamus, basal ganglia, cerebral peduncles and pons. Ventricular dilatation and atrophy of the corpus callosum also occur.

The characteristic pathological lesion is an angiopathy of small and middle-sized arterioles. Smooth muscle cells of the media are replaced with deposits of basophilic granular electron-dense material known as GOM (granular osmiophilic material). The basement membrane may be thickened and there is reduplication of the internal elastic lamina. Throughout the subcortical white matter as well as in the basal ganglia and thalamus of post-mortem specimens, there are multiple small lacunar and cystic infarcts.

The defective gene causing CADASIL has been mapped to chromosome 19 p 13.1. Joutel et al. (Nature 1996;383:707) have shown the Notch3 gene, which is in the CADASIL critical region, to contain mutations in CADASIL patients. Notch3 encodes a glycosylated transmembrane receptor, which in Drosophila is involved in cell-fate specification during development.

The exact mechanism whereby defects in the Notch3 protein cause the angiopathy of CADASIL remains to be determined.

For further information on CADASIL contact Dr. Edwin H. Kolodny of NY University School of Medicine or the United Leukodystrophy Foundation.

Further extensive in-depth research information is available on these subjects and more through the ULF library of printed and videotape materials. When requesting further information please let us know whether you are a professional or lay-person so that we can respond with the appropriate information level.

I want to go Public . . . I wish a media program or news would publish my story, or let me tell about CADASIL as this is so rare that there are many people out there who have been misdiagnosed and no ones knows what we have to live with each day.

I would like to also start a CADASIL Foundation here in the U.S.A. and if anyone has any ideas on how to do either please let me know at cadasil@earthlink.net

If you would like to be on the list for this newsletter or a contact person on the worldwide support group please contact Billie. Please e-mail or mail me your e-mail or address to

Billie and Steve Duncan-Smith
CADASIL support group
3605 Monument Drive
Round Rock, TX 78681
512 255 0209 home

You can contact other families who are also going through this nightmare. REMEMBER YOU ARE NOT ALONE looks at www.home.earthlink.net/~CADASIL/sup.htm for others who are need support or going through this also.

Please remember this newsletter is to help others. I do not want to mislead anyone. I am looking for HOPE, link to others with CADASIL, and find out as much about this disease as possible and hopefully a cure one-day. I m not in the medical field or claim to be a professional on CADASIL.

Print this newsletter our to anyone in the medical field or family and friends. The more people who know about CADASIL the more HOPE WITH HAVE TOGETHER.

CADASIL
Together We Have Hope