



Dear Parents,

My name is Claire Richardson and I am presently completing my clinical doctoral studies in occupational therapy through Creighton University, Nebraska. This is the second letter I have posted this year (2007) about pieces of research being conducted, and I am once again appealing for help with my research into Adrenoleukodystrophy and Occupational Therapy services.

#### The Study

This will be a qualitative, interview based study pertaining to the experiences of this diagnostic group, and it is my hope to work with parents and patients diagnosed with ALD. I am looking specifically at;

- 1) The disease process and how the illness presents in 'real life'.
- 2) How the disease changes over the course of time.
- 3) What functional impacts this has on day to day life on a functional, practical and emotional level.
- 4) What would help to best deal with these changes over time
- 5) What services are commonly received, and how easy are they to access.
- 6) What services are commonly lacking

These are some of the areas I am interested in exploring as I believe it will add to the information gained from my first study, when I worked with occupational therapists who provide direct therapy services. I hope to do two things with this information 1) publish the information in a research based journal to increase the knowledge base of practicing therapists around the country. 2) To develop some resource literature available to both parents and therapists related to the disease progression and what one can expect, as this information is presently lacking unless parents are able to connect with each other and exchange information.

It is my belief that these pieces of information will assist both families and therapists to deal with and plan for this diagnosis and ensure appropriate team care can be implemented.

If this is something you would be interested in participating in I would appreciate it, and look forward to hearing from you. If you had previously sent me contact information for my last study, and are interested in participating in this study, please send me a second set of contact information. This will allow me to determine who is interested in this second stage of my research and prevents me from contacting someone that would prefer I not.

Thank you for your assistance, if you or anyone else has questions pertaining to this letter, or is interested in participating in this study, please feel free to contact me at the below address. You can also send me an email so that I could follow up with additional information in a short time. Please use the title line "*Interested in the parents ALD study*"

Sincerely

Claire Richardson  
Occupational Therapist  
Creighton University Doctoral Student

Please forward additional information regarding the occupational therapy study relating to Adrenoleukodystrophy to me using the methods listed below. Please check the response at the bottom of the form as appropriate:

NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

PHONE \_\_\_\_\_ FAX \_\_\_\_\_

EMAIL \_\_\_\_\_

Responses:

I am sure I want to complete the questionnaire, simply send it to me when it is ready

Please send me more information about the study so I can decide if this is something I want to complete.

Claire Richardson  
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