

Summary of ECD Global Alliance chat held on Saturday 16th October 2010

7 Present:

- Approximately \$3000 has been raised to date from the 10/10/10 campaign. An organizational status will be sent soon and will provide an exact amount.
- A member has contacted a local school to enquire whether they would be willing to participate in fundraising for the ECD Global Alliance.
- One member is organizing a fundraising event with a local restaurant, whereby 15% of the gross proceeds would be donated to the group.
- Two potential ECD studies are still in the approval phase, the NIH study and Dr. Vaglio's study in Italy.
- One patient mentioned they had recently been suffering from headaches. This patient was exposed to Freon gas in their mid 20s and was intending to mention this to doctors at their next consultation.
- A question was raised as to whether anyone had heard or been prescribed Low Dose Naltrexone (LDN). No-one on the chat had any experience of this drug. In its normal dosage it is thought to be used to counteract the effect of opioid drugs. It has been suggested that it might be used off label at one tenth of its normal dose to treat ECD. There have been some interesting results with this drug with several autoimmune diseases.
- There was a discussion on the difference between the terms 'remission' and 'stable'. A member commented that 'remission' is really when there are no signs/symptoms but the disease is still there, just 'asleep', whereas 'stable' refers to when it is not changing but may still be bothering the patient.
- There is differing opinion about listing the names of those who donate to the organization. Some think this is a good idea and others would prefer their privacy to be maintained. If a person donates in someone's memory then the organisation lets the family/relative know that a donation was made. Some anonymous donations have been made to the group. Letters of thanks are sent to those who make donations. The organization at present errs on the side of protecting privacy.
- There is no summary for the October 9th chat as it was very brief with few members participating.
- The next chat will be held on Saturday 23rd October 2010 at 3pm EST.