

ECD Global Alliance Internet Chat Summary Chat on 11 Feb 2012

Attendees: 7

- There were prolonged discussions about snow! Who had it, and how much did they have? Who would like some, and who could get a truck full, and bring some to the snow-deprived?
- A member, who is still managing to work, had had more trouble with speech, so that he couldn't be understood on the phone. This is worse when he is tired. He was otherwise OK.
- A member had sent some vegetarian recipes to another member who had a "veggie" coming to visit. A recipe for mushroom stroganoff had proved successful. The recipe is at the end of this summary. It is an English recipe, and so it will be in weights rather than volumes (grams not cups).
- A member who has been looking for alternative work has not had any recent interviews, but has already bought her plane tickets for a holiday in Florida, so who cares? She doesn't! The holiday will be in Stuart, where her family have a rented apartment. The member's sister is going too. Sand, sun, and shopping are on the schedule!
- This member has already been to Bethesda, but so far, her medical team do not seem to have changed anything. An appointment with the neurologist is due for botox injections. These are used to try and reduce spasm in the leg muscles. They haven't helped a lot.
- A member, who has had a PET scan recently, has not heard anything about it yet (no news is good news?).
- Most of the rest of the chat concerned Rare Disease day, activities related to that, and a discussion about getting the media interested in our story.
- Rare disease day is always on the last day of February. That is the 29th this year because it is a Leap Year. 8 people have been able to give a commitment to being in the Bethesda/ Washington DC area on Feb 29th. They will be going to Capitol Hill to do some lobbying, and going to Bethesda to tour the NIH. On the next day there will be meetings at the NIH and an evening "reception" and dinner.
- In Kathy's community (in Louisiana) they are having a 5K/1mile run/walk on March 24. They are trying to tie the publicity of that, to Rare Disease Day. There are two high school girls who are coordinating the run (proceeds go to the ECD Global Alliance). They are focusing it on rare diseases in general, and doing radio interviews/club appearances to talk about it all. They have been invited to talk in a large church next week, and they have a TV interview scheduled as well.

A press release about the girls organizing a fun run brought no response. But this week the girls were invited to speak at the county planning meeting, and the local Rotary Club. Suddenly the press became more interested (it remains to be seen whether the local paper runs a story or not!).

- Some members have tried to get publicity in their own areas, but without success. Getting publicity is a difficult thing to do. It is the slow and steady approach that seems to work. In Kathy's community, the press becomes much more motivated to cover the stories, when people are out trying to do something to help, rather than when a press release is sent, about something that is happening. When the press see people gathered to make a difference, they realize it is more important and that their customers will be interested.
- A member had, last year, sent a press release to an editor he knew, but it was not "local", and the editor wanted no part of it.
- A guide has been developed for anyone who is interested in putting on a fun run, explaining the steps. If you want to put on an event, there are probably instructions on the internet, that will tell you how to go about doing it.
- The local press and local TV want to cover the local news. It is thought they really can't compete with the national media on anything else. So, it seems if you want coverage it is easier to make it happen if it is about something happening in the local community.
- Civic clubs (Rotary, Lions, Kiwanis, Jr. Women's, etc.) all like to have guest speakers. You can go speak to them about the subject. Most clubs like to promote the work of their organization, and thus will help put a picture and short article in the paper about the meeting! It is a foot in the door.
- It was suggested to a member, with an interest in photography, that it would be fun to try to set up a "Camera Shoot" with a "record" number of people in a town supporting Rare Disease Day or the GA. Suddenly it is about a local happening!
- A member will have her photo at the Liam's Lighthouse Foundation NYC event on the 24th and 25th, on the Today Show.
- Our weaving member has had a slow week with her hobbies. She is having to devote time to getting all the "tax stuff" ready! Her back is still slowing her down. It had been doing great as long as the "magic" tape was used, but she tried a few days without it, and that was not a good idea! So now she's taped again, and hoping it will ease soon, although the tape is not as effective this time as it was before.

MUSHROOM STROGANOFF

Serves 4

500g mushrooms, wiped and quartered

1 medium onion & 2 cloves garlic, all chopped and minced up together

30ml oil (olive or vegetable)

100ml red wine

3 tbsp of creme fraiche or double cream

1 tbsp balsamic vinegar

1 dessert spoon corn flour

1 level tsp paprika

1 handful of freshly chopped coriander

Soften onion and garlic in oil over low heat, until starting to brown.

Mix the mushrooms and paprika (eg in a plastic bag)

Add mushrooms to onion and cook for 5mins until soft

Add balsamic vinegar

Mix corn flour with a little water to make a paste and add it

Add cream and coriander and mix it all well.

Serve with rice or bread