

NEWSLETTER 10
July 2013

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Dear Councilors 2012-2013 (President and Vice President 2012-2013)

Dear Agora friends,

Time to start booking for the conference!

Let your voice and your country's voice be heard on the conference!

And most of all: Come join the Agora fun...

COME AND JOIN US AT THE
ACI AGM 2013 - HYERES



From the 10th to the 13th of October
The beautiful south of France
will be inundated by
Agora ladies from all over the world!

Don't miss it!
BOOK NOW!



Find all information about the weekend, registration forms
and programs on our website:

www.agoraclubinternational.com



INDEX NEWSLETTER

1. Important dates	
• Next 3 months	Page 2
2. Reports of the ACI Board about:	
• Welcome to two new individual members by Veerle	Page 3
• AGM AC Belgium by Veerle	Page 4 - 5
• ACI conference in Hyères –Hotel Plein Sud	Page 6
3. Reports Countries	
• Year report AC Brasov 3, Romania by Dora	Page 7 - 8
• AGM AC Italy by Letizia	Page 9 - 10
• AGM AC Morocco by Narjisse	Page 11
• Countries in the picture – USA by Kelly	Page 12 - 14



IMPORTANT DATES

Next 3 months

- 21.-24. August LCI AGM in Lusaka, Zambia
- 28. August-01. September RTI AGM in Valence, France
- 21. September Charter AC 7 Tours, France
- 07.-10. October Boardmeeting 5 in Hyères, France
- 11.-13. October ACI AGM in Hyères, France
- 14. October Boardmeeting 1 and 2 in Hyères, France

Reports ACI

Welcome to Agora !



Elena Charalambidou (Cyprus) , Veerle, Ashwini Surendar (India)

During holidays we spent together, two former LCI Presidents,
but most of all two *dear friends*,
decided to join Agora Club International as individual Members.

Welcome to our world wide web of friends dear Elena and Ashwini !

Veerle xxx

AGM Agora Club Belgium

By Veerle De Jonge

After months of travelling to our Agora countries for AGM's, Charters, festivities etc, it was nice to be on "home turf" again for the Belgian AGM...15 minutes drive and I was there ! What a luxury ☺

On the 29th of June 2013, all 15 clubs of AC Belgium were present to "Share their Passion".

ACB President Karine's Club AC 12 Wetteren did a marvelous job in organizing a warmhearted and fun AGM.



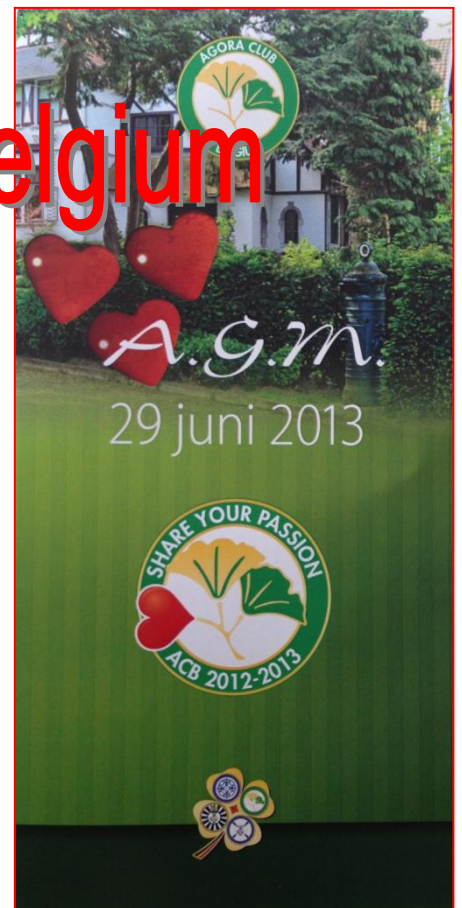
The Ladies of the National Board (all in passionate red) ran an impeccable AGM, with time for work, emotion and laughter. An example on how an AGM is conducted, well done dearest friends!



There is a strong spirit of "4 Clubs 1 Vision" in Belgium, and the fact that the National and local Presidents of all 4 Clubs (AC + LC, 41 Club and RT) were present at the AGM, showed the importance and value of this co-operation.



What a pleasure it also was to welcome representatives from AC The Netherlands and even AC United Kingdom too, all the way from AC Noordwijk and AC Southend-on-Sea.



The AGM ended with the official induction of the new AC Belgium Board. Good luck VP Pascaline, IPP Karine, P Yvonne, Treasurer Carine and Secretary Mimi! I am sure you will all carry AC Belgium into an ever brighter future!



That same night I was so happy to home host Sandra, Louise and Nikkie from AC Southend-on-Sea. Karin, Greet and Mimi from my own Club joined us for a visit of Gent, we made a little boat trip, and had a lovely dinner at my dear friend (and AC Belgium Tresaurer) Carine's restaurant in Gent. What a GREAT AGM weekend it was!



Photo opportunity at the most beautiful bridge in Gent



Angels : YES! But fallen??



Always tons of laughter with the Southend ladies ☺



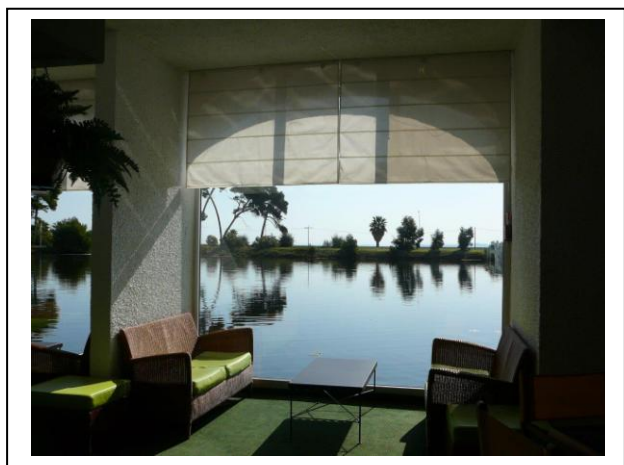
An absolutely lovely friends-night out!

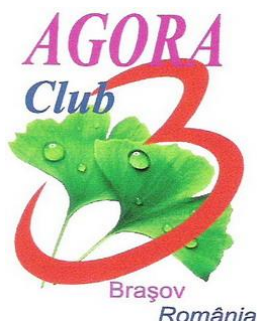
ENJOY!

ACI AGM 2013 - HYERES

Impressions of Hotel Plein Sud

We will surely enjoy the water -inside or outside





“FRIENDSHIP IS ALWAYS A SWEET RESPONSABILITY NEVER AN OPPORTUNITY”

Dear friends of Agora Club - 3 Brasov,

I would like to summarize the period comprised between January 2012 – June 2013. The brave ladies had the initiative of forming a new Agora Group in Romania and, in time, managed to bring together more friends. On November 10, 2012 they accomplished their objective through their sustained effort and with the help of the Agora International Board. The Charter Meeting is the first important moment club's life, and in our case it was successfully accomplished through the endeavour of its members. The compliments we received and the presence of the International Agora President Veerle motivated us towards action in the period that followed. All this time, as a President, I have tried to extend and consolidate our friendship and connections with all the clubs in Quatalagor (that is with Club 41, Round Table, Ladies Circle and Agora), by attending and representing the Club at as many events as possible:

- 20 years anniversary of Ladies Circle Brasov
- 20 years anniversary of Club 41 – 1 Brasov
- AGM Ladies Circle Romania
- MTM Ladies Circle - 1 Brasov
- Chartering of Agora - 4 Craiova
- Two AGMs of Agora - 2 Brasov
- All the events and activities of Club 41 – 3.

Moreover, it has not escaped my mind that the main objective of our club is the activity that benefits the community. Around the Winter Holidays, the energy and enthusiasm of the young club brought happiness and comfort to the family of a street musician (Humberto Aquilar). Hence selling his CDs and giving him the money was our first action. In April, our old bond with the association „Hospice Casa Sperantei” materialized into a charitable concert. The money that was raised by selling the tickets was donated to the association. I thank every person who helped us, all my friends in the club who mobilized their relatives and friends and managed to fill the concert hall.

In the past six months we have made our first steps towards the consolidation of this club (we have two postulants) and towards better knowing each other, becoming a „stronger through diversity”(motto’ Veerle). During this time, we have maintained our relationship with the International Bord which is keeping us up to date on everything that is going on in the Agora World.

I give my special thanks to our dear friend Veerle. I also thank our friends in England and Belgium who have honoured us with their presence at our Chartering in November 2012. By overcoming all the difficulties that arose in the beginning, and by using my experience in the Ladies Circle and in the Agora clubs, I believe that I have created the proper foundation for the creation of the *Agora National Association – Romania*, with the help of the other two existing Agora clubs in Romania.



Friendship forever,
DORA GRIGORI
President AC 3 Brasov 2012-13



Donner et Tolerer / Service and Tolerance

NATIONAL AGM AGORA ITALY (7-9 June 2013)

Dear Friends,

our AGM started on Friday 7th June with an incredible homeparty in Cristina's garden in Bologna. The Italian National Board with Elisabetta Ferin, Letizia Iulli, Donata Piccini, Luisa Maria Tabacco, Serena Cioffi together with members of Agora Bologna, Stefania Cinefra P AC Vicenza and some husbands gathered around our very welcomed AC International President Veerle de Jonge.



On Saturday morning, the Italian ladies together with Veerle, Claudine Schildhauer, T'angent Germany IRO , some members of Club 41 Bologna and Milano explored the town and visited some attractive historical places in the centre of Bologna. The long walk was amply rewarded with a typical Bolognese lunch.

Early in the afternoon all the Italian delegates met at the historical Palace Segni Masetti, where the Italian President Elisabetta Ferin also welcomed and thanked for their presence Veerle de Jonge, Daniela Bergantino IPP Ladies' Circle, Paolo Pisani and Augusto Ferrari National PPs Club 41 Italy.

Veerle's speech was very much appreciated. She also offered us to be Godmother to Malta Club and we all accepted with great honor and enthusiasm. (hip, hip, hooray)



Elisabetta introduced Elena Merlin: She will be the President of a new Italian Agora Club in Verona, whose Charter will be fixed for the end of the year. (hip, hip, hooray)

At the end of our discussions, with all the honors of the situation in “ *Pomp and Circumstances*” , *chiming of the bells, and trumpet blasts, the new National Board was invested* : Letizia Iulli President, Diana Brioschi Vicepresident, Elisabetta Ferin IP President, Luisa Maria Tabacco Treasurer, Serena Cioffi Secretary



(From left: Veerle, Diana, Letizia, Elisabetta, Luisa and Serena.)

Our Gala Dinner was cheered by Veerle, Claudine, Daniela Bergantino Ladies' Circle IPP and a large group of Club 41 Italian National Board. In this pleasant atmosphere, we found again the privilege of celebrating Friendship among Agora, Ladies' Circle, Round Table and Club 41 in the perspective “ Four Clubs, One Vision”.



From left: Daniela(LC IPP), Letizia NP, Veerle, Maurizio Belli (N.P. Club 41), Elisabetta IPP



During the Dinner we offered the Vice Mayor of San Prospero (Modena), Sauro Borghi, the funds Agora Club Italy collected in favor of the population around Modena struck by the earthquake in May 2012.

On Sunday, after visiting piously the Basilica of Saint Luca, all our ladies finished their Italian AGM in another tasty meal in the Bolognese tradition! The sacred and the profane together! It was sad to say “ Good bye”, but we promised to meet again soon and strengthen our friendship.

Thank you every body for coming to our AGM.

Thank you, Veerle. It was a great honor to have you with us (We do hope your Italian sprain is only a bad memory!)

In continued Friendship
Letizia Iulli, (Italian N.P)

PS: See you in Hyeres!

REPORT ON THE CASABLANCA AGORA CLUB AGM

We Casablanca Agora Club 1 members were delighted and honored, that the president of Agora International Board Veerle De Jonge had chosen to attend our AGM on June 22, 2013 in Casablanca.

Also present in the AGM were the presidents of the 7 Ladies Circle Clubs in Morocco and several of the members of Ladies Circle Clubs.

We all enjoyed listening in this friendly and warm environment to the different speeches delivered by the President of Agora International Board, as well as the speeches delivered by the Past President of the Casablanca Agora Club, the Secretary of Casablanca Agora Club and the national Secretary of Ladies Circle Clubs.

They all enhanced the principles and values that we all believe in and that guide our actions and social projects and shape our vision.

After the election of the new Casablanca Agora board for the year 2013-2014, we ended our meeting with the feeling, that we will treasure these special moments spent together united in joy friendship with a strong belief that our diversity is our enrichment

Here attached to this report some pictures of the AGM.

Narjisse Kaicer



The **Agora USA** ladies meet and share in many activities together, but the most rewarding and our main focus near and dear to our hearts has been supporting fundraisers and events for Niemann Pick Disease. It is for that reason that we turn over this article and opportunity to share Information to Karen Quandt. Karen has been an active board member and founding member of Ladies Circle Seattle and Agora Club Seattle. We hope this article shines some light on this rare and fatal disease that is being battled across the world as you will see as the article unfolds to include information from the International Chair Jim Green. With lots of love, perseverance and hope ~ **Kelly Geisler** ~ **Agora Club USA**



My name is Karen Quandt and I am the chair of the National Niemann-Pick Disease Foundation and the Vice-Chair of the International Niemann-Pick Disease Alliance. My son Ty, 16 years old has a neurodegenerative disease called Niemann-Pick type C (NPC). It is a rare, progressive and fatal disease.

The local Agora Club of the USA support my family in many ways to help us cope with this disease that is slowly taking away my son's ability to walk, talk, eat, think, and speak. The Agora club also helps my family fundraise for research into this rare disease.



The Agora club has helped to organize and participated in two 5K run/walks to raise money for the National Niemann-Pick Disease Foundation (nnpdf.org) in the last 12 months. The Agora club also purchased signs for the 5K race that educated participants about this rare disease. The signs along the 5K course said the following:

1. There are more than 6,000 rare diseases.
2. Nearly 30 million Americans or almost 1 in 10 Americans are affected by a rare disease.
3. Of those affected with a rare disease, 75% of them are children.
4. There are no treatments for 95% of rare diseases.
5. Collectively rare diseases are not rare.
6. Hope is a risk that must be run!
7. Niemann-Pick type C is a progressive neurodegenerative disease and is a rare disease.
8. Research is our hope for finding treatments or cures.





The Agora club has been fundraising for research since Ty was diagnosed 8 years ago. We were the Ladies Circle at that time. Thank you Agora Club USA for helping us to persevere for a cure for NPC!
Karen Quandt, Agora USA member

From Jim Green, chair of the International Niemann-Pick Disease Alliance, his INPDA article from the INPDA website ~

"An International Response to a group of diseases that present challenges that cross all national boundaries"

The International Niemann-Pick Disease Alliance is an alliance of non-profit support organisations who are associated with the rare group of genetic diseases known collectively as Niemann-Pick Disease. The Alliance was formed in October 2009 with a view to providing a forum where, through the exchange of information, experience and knowledge, progress could be accelerated. It is therefore, fundamentally, a network.

The following Aims were agreed at the first meeting :

- To focus on International Collaboration
- To learn from other Foundations
- To encourage foundations, researchers, clinicians and industry representatives to meet regularly
- To develop strong networks - face to face contact
- To identify shared goals and address common challenges
- To co-ordinate access to clinical trials and therapies
- To create a stronger voice re. health policy
- To share ideas and practice regarding research and clinical trials

At present there are 10 separate foundations in the Alliance.

[Argentina](#)

[Canada](#)

[France](#)

[Germany](#)

[Italy](#)

[Netherlands](#)

[Spain](#)

[Switzerland](#)

[United Kingdom](#)

Asociacion Niemann Pick de Argentina

Canadian Chapter NNPDPF

Vaincres Les Maladies Lysosomales

Niemann-Pick Selbsthilfegruppe

Associazione Italiana Niemann Pick

Volwassenen, Kinderen en Stofwisselingsziekten

Foundation Niemann-Pick de Espana

NPSuisse

Niemann-Pick Disease Group(UK)

www.npc.org.ar

www.nnpdf.ca

www.vml-asso.org

www.niemann-pick.de

www.niemannpick.org

www.stofwisselingsziekten.nl

www.fnp.es

www.npsuisse.ch

www.niemannpick.org.uk

