



Alzheimer
Gesellschaft
München

Mit neuer
Zuversicht!



ASSOCIATION
FRANCE ALZHEIMER
VAUCLUSE

Un malade, c'est toute une famille qui a besoin d'aide

MEETING WITHOUT FRONTIERS RENCONTRE SANS FRONTIÈRES

14. - 21. MAY 2012

An exchange, under the supervision of a team of professionals, between "ALZHEIMER GESELLSCHAFT MÜNCHEN e.V." and "FRANCE ALZHEIMER VAUCLUSE" for people with Alzheimer's disease and their partner



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HEIKE VON LÜTZAU-HOHLBEIN

President of "Alzheimer Europe"

To go on holidays together to a foreign country, holidays which would bring new impressions and moments of relaxation is almost impossible in the life of a couple where dementia rules the day. The difficulties of such a trip have become seemingly insurmountable. I am all the more pleased that the "Alzheimer Gesellschaft Muenchen" (Munich's Alzheimer Association) together with "France Alzheimer Vaucluse" (Avignon's Alzheimer Association) had the courage to create the project of "Meeting Without Frontiers - Rencontre sans Frontières - Begegnung ohne Grenzen". The active support for the planning and realization of this vacation otherwise experienced difficulties fade into the background. Sharing activities with others who have the same illness within a protected framework as well as having experiences in common in a foreign environment can give new strength to everyday life back home.

Exchange and common projects between different European countries, including those that concern the field of Alzheimer's disease are wonderful ways to bring to life the idea of a "united Europe".

As president of "Alzheimer Europe", I very much welcome the idea that the existing national support services, together with Alzheimer patients and their families, set up professionally-supervised projects that cross the borders. Alzheimer associations, with their potential of independence and creativity are being challenged to find new ways to increase the competence of Alzheimer patients and their families.



Heike von Lützu-Hohlbein
President of "Alzheimer Europe"



PREFACE

MARIE-ODILE DESANA

President of "France Alzheimer"

"Sharing, solidarity, friendly relations", the basic values that characterize this project are also those that characterize the underlying ideas of the National Union of the France Alzheimer Associations since the beginning of its existence. This trailblazing project demonstrates how important it is, in spite of the disease, to continue having new experiences and discovering new horizons. It also shows a perfect illustration of how innovating projects such as these can help patients and close relatives to open up, to make new contacts with other families, to create better relations with professionals, to share their personal experiences and to gain renewed confidence. These are the very objectives that France Alzheimer has always pursued in all its undertakings.

Furthermore: "Meeting Without Frontiers" also has a positive impact on inter-European relations. The meeting of families of two different cultures obliges them to momentarily forget their daily routines and the difficulties brought about by the illness; they are then free to simply profit from this time of happiness and friendly exchange.

I congratulate the French and German associations who had the audacity and the will to initiate this project "without frontiers".



Marie Odile Desana
President of "France Alzheimer"



PREFACE

BEATE ÖZTÜRK *President of “Alzheimer Gesellschaft München e. V.”*

DANIÈLE NAHOUM-SOKOLOWSKI *President of “France Alzheimer Vaucluse”*

Dear families and friends of Alzheimer associations and those concerned by Alzheimer’s disease,

In this press-book you will find the account of an extraordinary meeting: “Meeting Without Frontiers” that took place between the German Alzheimer Association of Munich and the French Alzheimer Association of Vaucluse, Avignon.

Since years these two organizations deal with those who have Alzheimer’s or a related disease and their families, with one objective in mind above all: to be creative in their approach and to elaborate, together, new proposals for accompaniment and support.

Several members had suggested going on a trip together: a desire that needed to be put into action. At the same time, the already existing ties between our two Alzheimer associations became stronger. It was thus very naturally that the idea of an exchange emerged.

This trip? An innovative idea and, as far as we know, it is a first-time endeavor for such a project. What an enormous challenge for all participants! We would like to say a big “thank you” to all those, on both sides, who have contributed to the preparation, the organization and the realization of this project.

While leafing through the pages of this press-book you will discover the basic spirit of the project and its different aspects. We have given priority to what was said by patients, families and accompanying staff members. You will see that the themes of “normality” and of “joy” became the “central thread” all throughout this event. During this week, the illness and its constraints took a back seat. No frontiers existed between the families, who felt completely free to communicate and to share experiences. It was no longer of any importance to know which member of the couples had Alzheimer’s disease and which one did not.

We are very proud of this project. And we express the wish that other families and other organizations could enjoy similar experiences. We greatly encourage them to break new ground, to cross borderlines, to overcome fear, to create new ties and to find new ideas for living together.

Sincerely,



Beate Öztürk

Beate Öztürk

President of “Alzheimer Gesellschaft München e. V.”



Danièle Nahoum-Sokolowski

Danièle Nahoum-Sokolowski

President of “France Alzheimer Vaucluse”



14
MAY

DAY 1 - ARRIVAL AND RECEPTION AT THE GERMAN CONSULATE IN MARSEILLE

Munich - Marseille

Marseille

WERNER PAUS

Affected

“I am very lucky because I can see the sea. It is pleasant to be here and to be able to observe such immensity.”

WALTER OBERST

Partner

“This trip and the return trip, with our French partners is an example of the European model.”



CHRISTINE PAUS

Partner

“It is like a dream; I still cannot believe that I am here. On account of my husband’s illness, I never thought that we would someday travel to Provence. But, thanks to the organization and the attentive care, our dream has come true. Otherwise, we would never have found the courage.”

IRENE HINRICHSEN - CONSUL GENERAL

Volunteer

“It is with an immense pleasure that we welcome the group from Munich to the German consulate. We offer you the use of our parking lot for your cars and we are preparing a convivial brunch in our courtyard.”



TOBIAS BARTSCHINSKI

Professional

“We’ve decided to share a house, which is to say we intend to live together as one big family, a family that will organize its own ‘normal’ everyday life. Some couples already know each other. It is the already existing - and fundamental - atmosphere of confidence that allowed us to submit this idea to the participants. Each person knew that he/she could freely decide whether or not to participate in various activities.”

LISA JUNGLAS

Professional

“The German consulate in Marseille showed great interest in the German-French exchange program. The participants in ‘Meeting without Frontiers’ received a personalized welcome at the consulate devoid of any preconceived prejudice.”

COMMENTARY BY A PROFESSIONAL

When Alzheimer’s disease appears on the scene of a couple’s life, new tasks also appear, the partners’ roles change and difficult situations in everyday life become more and more frequent. Organizing any trip is a luxury. So, any such leisurely activity, away from their daily routine put together by an extramural organization is perceived as a blessing.

15
MAY

DAY 2 - TREKKING WITH DONKEYS

A therapy by means of animals

Bollène

**FABIENNE PIEL***Affected*

“I encountered a seemingly normal group of participants without at first realizing that they were ill. We came together without any preconceived ideas. Certain partners were vigilant but never too intrusive so that everyone could feel at ease. It is not because we are ill that others should feel they can dictate to us what we should do. As sick people we want to be able to make decisions for ourselves. My project has once again been realized. A donkey is an animal that can be led, that is patient and that can learn how to carry heavy loads. My two donkeys, Pompom and Moustache, created for me the link that allowed me to come in contact with the other participants. I do not understand German but I found myself connected to the group by a common cause.”

WERNER PAUS*Affected*

“The walk with the donkeys was a great moment. I led the donkey. It was a wonderful entertainment.”

RENATE TRÖGLER*Partner*

“My husband is the body and I am the head. In everyday life we are complementary in supporting each other. During the walk we felt relaxed. All the participants helped each other.”

HANNELORE DE PAOLIS*Volunteer*

“I spoke with the afflicted. At first the illness is not noticeable. They are extraordinary people.”

**LISA JUNGLAS***Professional*

“During the walk, I observed that the sick took responsibility for their donkeys and that they shared this responsibility with their partners and other participants. Thus, the partners were able to appreciate their loved one in a different light. Personal experiences and memories were shared.”

COMMENTARY BY A PROFESSIONAL

To view an animal as a fellow collaborator and to enter into a kind of complicity with it by being responsible for it shows us that those afflicted with Alzheimer’s disease are very sensitive and are able, despite the limits they encounter in any interaction, to find a way to use their abilities and thus reinforce their self-confidence. The encounter with the donkeys was both natural and without stress.

**CHRISTINA OBERST-HUNDT***Affected*

"We danced until midnight. I feel free and rested."

SEPP FRIEDRICH*Affected*

"If I have difficulty finding my room, I go to the kitchen and ask someone to take me there."

**TANIA KRAUS***Professional*

"The most moving episode was where the men were sitting around the table peeling vegetables for the next meal - a meal for which they were solely responsible. In this atmosphere of 'camaraderie' they felt free to share jokes 'amongst men'. You could perceive with which euphoria they seemed to be rediscovering and savouring their identity, the 'real' one, no longer that of a sick person."

**ULRICH LANGE***Affected*

"When I could no longer work because of my illness, I was depressed. It was difficult for me. I need sports and here I can walk and dance."

**MARTINE RUIZ***Volunteer*

"When it came to finding some help to chop up the vegetables, I was surprised to come upon a table of men whom I knew to be ill. It was a new experience for me to see how they gave each other mutual help and motivation."

BARBARA V. FRIEDRICH*Partner*

"There were some beautiful surprises such as making the 'Pistou' soup together. And, I will never forget the cherry tree. I have never eaten so many cherries at once."

COMMENTARY BY A PROFESSIONAL

The achieving, on their own, of tasks important for others, and without being directly 'controlled' has a positive impact on the group and means: living inclusion. The feeling of being useful to others, as well as the realization of one's own personal worth, is all too rare in their everyday existence, and this absence weighs heavily on their mood. To be together in a very open and normal environment creates an impression of lightness, a feeling of peace and a sense of freedom.



JOSEF KRAUS
Affected

“What a pleasure to be able to speak with people. We are often alone with our own thoughts. How fortunate! Munich has come to us: what a brilliant idea! All of the people are nice and the conversations are interesting - and in my mother tongue. It is wonderful to be able to use my language skills again.”

BARBARA V. FRIEDRICH
Partner

“Visiting Hannelore and Renato in their home is an unforgettable experience. Thank you so much!”

TANIA KRAUS
Professional

“After the meal I proposed that we do some exercises, and this very heterogeneous group came together (in all senses of the word) to do relaxing movements in the pine forest. And that brings me, as a therapist, to ask myself a question: is not the best therapy that which, even if set up by professionals, expresses itself in a totally ‘normal’ context? Have we not all too expediently created ‘ghettos’, thus creating a situation of pathogenic isolation?”



HANNELORE DE PAOLIS
Volunteer

“I truly enjoyed having them to our house for lunch, showing them our garden, and offering them ‘chaises longues’ for their nap. It was so harmonious.”

ANDREE DUCROQUET
Volunteer

“It is such an exceptional house, and it was so pleasant to be able to share with my husband that moment spent at the pizza oven.”

COMMENTARY BY A PROFESSIONAL

The patients and their families speak of the fact that friends and members of the family often distance themselves after hearing the diagnostic. Invitations become rare, yet they are so important. The possibility of meeting other people outside of one’s own four walls is a relief and helps to make life easier and to loosen the tensions, they encounter so often.





JOËL FAUQUET
Affected

“I felt that we all spoke the same language. It was all so natural. I didn’t even notice that there was an interpreter. The people were respectful, interested and attentive. It was the very first time that I guided a group of German tourists through Avignon to show them our precious cultural heritage. Then, he laughed and added, “Is this the beginning of a new career?”

AGNES FAUQUET
Partner

“For the first time I found myself dancing with my husband on the ‘Place du Palais des Papes’ (in front of the Popes’ Palace). It came about all by itself. I wanted to show ‘provençal’ dances to the group and then ever so naturally others joined us. There exists in the group an atmosphere of life and not one of illness. I am willing to relive the experience in Germany next year.”



BRIGITTE FIEGER
Professional

“The professional accompaniment of the group is a basic necessity for ‘Meeting without Frontiers’. Prior to the trip, we participated in a first aid course. Throughout the stay, we must have ‘antennas’ and be present at all times. These conditions permit those who are ill to feel secure and thus to be independent.”

HANELORE DE PAOLIS
Volunteer

“I have learnt how to support and accompany a person without being bossy and without smothering him/her with my help.”



COMMENTARY BY A PROFESSIONAL

“Everyone has skills which must be kept up, otherwise it wastes away. Often strength alone does not suffice, the spark to start the fire is lacking. A fire was lit during this encounter, inside a professional framework. The results were tangible: vitality and independence.”



WERNER PAUS
Affected

"Here one is drawn to exchange personal experiences with other people similarly afflicted who are of another nationality."

WALTER OBERST
Partner

"The stay here is very important for my wife for she feels respected here. This pause is essential for a couple because there is often a lot of stress in their everyday life. My wife can take part in everything; she is not excluded."

CHRISTIAN DUCROQUET
Affected

"It is important for a group to be well received and well treated. That gives enormous pleasure. I cannot wait to go on our trip to Munich. I do not know that city."

HERBERT WIESENT
Affected

"At home I use a telephone system with GPS. I take it with me when I go to the city. It makes me feel secure. I recommend it."



MICHELE SANS
Professional

"It is as if we had known each other forever. One can feel that we all have the same way of facing this illness. It is regrettable that we do not all speak the same language, as we would have a lot to talk about."

MARIE BERTHET
Professional

"I felt a lot of humanity and attentive sensitivity when in their company - and lots of suffering. The fact that one does not speak the same language makes one sense the suffering all the more intensely.... The trip offers the opportunity for the participants to recover their energy because when you are sick it is not often possible to do so. Unfortunately, in our society, those who have been afflicted with Alzheimer's are rarely considered to be the equals of those more fortunate."

COMMENTARY BY A PROFESSIONAL

To feel welcome without being compelled to defend oneself each time 'right' words don't immediately come to mind, is an immense appeasement. This feeling is all too rare in the existence of those who have this illness.



GEROLD TRÖGLER
Affected

“It is a good group, which is rare. I did not think I would return to France. Despite my sickness, I was able to relax. And, what is more, it allows for the couple to momentarily separate, which is a good thing because the sickness obliges us to be always together.”



WALTER OBERST
Partner

„I have seen that each couple is dealing with the illness in a different way and that each couple has to reinvent itself after the diagnosis. That gives me hope that we can overcome our difficulties.“



BIANCA BRODA
Professional

“Independence is an essential factor in the life of an Alzheimer patient. But, at the same time, we must also take into account that the illness imposes its own limits. We, who accompany them, must constantly be very attentive.”



DOKTOR BERNARD SENET
Volunteer

“Language barriers fall: the mutual understanding expresses itself through the way one looks at one another and in the respectful manner shown when encountering someone. One lives the illness together, sharing one’s concerns and fears with those who are sick and with the families, all of which renders the illness more tolerable without necessity for words to express oneself. This does not, in any way, take away the merit of the super interpreter and organizer nor her choosing such a magical setting!”

CHRISTINA OBERST-HUNDT
Affected

“In this group we have the possibility to be alone and to do whatever we want to do. Everything is easy and simple.”

COMMENTARY BY A PROFESSIONAL

The partners can perceive each other from new angles. Unburdened of stress and the obligations inherent in the everyday organization of the couple’s life, it becomes possible for each member of the couple to respond to the other’s needs, to be more aware of his abilities and desires. In this way, they grant each other his/her space. This freedom is all too often suppressed by the fears caused by the illness. The participants were able to get to know each other individually.



NANNA KRAUS
Partner

“I believe that this illness creates a lot of suffering for those closest to the sick person. So, one can say that this week full of adventures, topped off with an evening of songs was in any case beneficial. I appreciated the merry atmosphere and the human contacts. I also broadened my understanding of the illness, gained more knowledge about it and that helps me to better comprehend the person who is sick. The organization could not have been better. It was prepared with love and was a one hundred percent success.”

JOSEF KRAUS
Affected

“I take the illness with humor. If I do not find the words immediately, I tell myself that I can wait.”

DANIELE NAHOUM
Professional

“The problem of language and the impossibility of translations to perfectly render people’s thoughts put us all in an equal position. Nevertheless, there was a ‘floating barrier’ and various ‘footbridges’ to cross over. We could not say with words why we were there but we could live the experience.”



LISA JUNGLAS
Professional

“The week went by in a more than satisfactory way. Thanks to the many months of preparation with colleagues from both countries, we could set up a framework that allowed each participant to freely decide for him/herself whether to be in a group or to simply spend time alone or with his or her partner. The team work and the solidarity between all of the participants have made for an enriching experience, on both a personal and professional level.”

HANNELORE DE PAOLIS
Volunteer

“It was a unique experience for me. This illness must not remain hidden, it should not be a taboo. It needs to come out into the open, to be made a public issue. I approached the sickness, I offered concrete participation, which is a way of being present and attentive.”

COMMENTARY BY A PROFESSIONAL

The project and the positive feedback confirm us in our idea to take new paths, to listen to the wishes of our patients and of those close to them and to make their wishes come true. We are looking forward to again sharing experiences together with a return visit (of the French) to Germany in the autumn of 2013. It is hoped that, in the future, the encounters may also take place within our own country, across the borders of the different ‘Länder’.





CONCLUSION

CHRISTINE ZARZITZKY M.A.

Managing Director of "Alzheimer Gesellschaft München e.V."

One of the goals of "Alzheimer Gesellschaft München" (Alzheimer Association of Munich) is to support those projects that tend to increase the capabilities of Alzheimer patients (and those who have related diseases) and their families and to facilitate them to take care of their own needs. This had already been the goal of our association's founders 26 years ago. The project "Meeting without Frontiers" has definitely succeeded in reaching this goal. The vacation trip, jointly planned, prepared and successfully brought to realization by our team of professional workers as well as our ill members with their families, leaves memorable and indelible traces for all those concerned.

"With newborn hope"! It is this motto of our association that reflects the way our members and their families confront the challenge of Alzheimer's disease, thus giving them the necessary feeling of confidence that helped them to make the decision of participating in the trip. During the holidays, everyone was striving towards active participation: to communicate with others, to laugh, to share thoughts and activities. Sharing one's own personal experience: learning how other ill people and their partners live with the disease and what their different needs are to be able to confront the illness; all these aspects of the exchange gives each person inspiration and energy to find his (her) own way of managing the situation. Renewed courage is thus found for confront everyday life.

The project of these holidays was also a challenge for those colleagues who work at the Alzheimer Centre, even more so because we had no previous experience in that field. The preparatory work was an additional charge to that which is already done at our consulting centre. Invisible to outsiders, this work was intensive: setting up various applications, for example to find solutions for financing, writing reports, electronic mail, going regularly to reunions... all of this was necessary to make these holidays a success. Such a project could only be set up and realized thanks to very motivated colleagues, willing not to count the time spent, having the courage of originality, breaking new ground. Not only did they learn much from the patients and their families, but the exchange with their French colleagues was also very enriching, as it brought into the open that each country or culture has its own perception of what the terms "Alzheimer's disease" or "dementia" mean.

As president of the "Alzheimer Gesellschaft München" (Alzheimer Association of Munich), I was very happy to support this project. The challenge of finding new ways to answer the needs of people with Alzheimer's disease and their families made it worth-while. It is through this joint initiative, and thanks to all of the help and support given, that that which usually remains unknown outside a small circle of people could become visible for the public. It is a group of seven couples who benefitted from this project. One can only hope that many other people will be able to benefit from similar offers in the future. The capacity to care for one's own needs was well illustrated in this project "Meeting without Frontiers", as was demonstrated by the atmosphere of serenity, of joy and of complete "normality" that prevailed throughout. It has now become our goal to encourage other groups and organizations find new ways and set up "normal" projects in other fields, thus reducing the number of barriers usually encountered up to now by patients and their families.



Christine Zarzitzky M.A.

Managing Director of "Alzheimer Gesellschaft München e.V."



CONCLUSION

DANIÈLE NAHOUM-SOKOLOWSKI

President of "France Alzheimer Vaucluse"

At "France Alzheimer Vaucluse" we are all affected in our own personal lives by Alzheimer's disease: a father, a mother, a partner, a friend... someone close to us has given us signs - often very discretely - that something in his (her) existence has changed, that something has been made different, either by a hint, a suspicion or the revelation of a terrible diagnosis.

At the same time we are professionals, trained to lend a listening ear, to help in counseling, to accompany in various ways, as therapists... We offer our services, hoping to be effective and to find solutions to the encountered needs.

Yet, not being in the position of Alzheimer patients (even if, deep down, we have considered that possibility), we are standing on the outside, complete strangers to what they are experiencing inside. One person who had cancer shared his feelings on an internet forum: "The patient is alone with his anguish (...) his isolation is concrete, it's not a movie, there is no stand-in, it is not just a play on stage. If you are sad one day, you can share that sadness with no-one else than yourself (...) It's very important not to show too many negative feelings with one's family and friends (...) There are simply some things one must keep to one's self and only share that which is positive. It is important to keep a personal space of privacy." It is due to this experience of solitude that we know nothing, or very little. And the little we know can only be learned directly from those concerned, provided they have enough confidence in us to talk about it.

Confidence?

They will have confidence in us if we go along with them, side by side. And that is what we do in order to be in harmony with each person: no one tries to think, act nor speak on their behalf... especially not we. It has become clear to us that only they are capable of expressing their feelings, desires and needs to others... But we "others": are we capable of listening? Caught in a sort of maelstrom in an intense movement of agitation, we are irresistibly swept into a state of extreme emotions: love, hate, along with all their possible gradations, and the need to have a hold or grip on others, authority, control; as well as feelings of abandon, of giving up, of resignation... To announce a diagnosis of Alzheimer's within a group of people is like declaring war! We propose to play the role of mediators, of "casques bleus"; we try to help those concerned to maintain peaceful, smooth relationships in their family and professional circles.

If boundaries exist, they separate us and they protect us from one another.

But we know that those boundaries can be crossed to meet those on the other side.

And that is exactly what we wanted to do by setting up this project of "Meeting without Frontiers" - "Rencontre sans Frontières" - "Reisen ohne Grenzen".



Danièle Nahoum-Sokolowski

President of "France Alzheimer Vaucluse"



CONCLUSION

FABIENNE PIEL

Member of the Board of Directors of “France Alzheimer Vaucluse” - Author of the book “Afraid of Forgetting”

Dear friends, dear fellowmen,

The experience of this project has shown us that we, who have Alzheimer's or a related disease are capable of participating in “normal” activities of everyday life. We could all enjoy a feeling of freedom and of reassuring security at the same time. We could show our handicaps openly and talk about them freely. We felt respected without any prejudice overshadowing the way we were considered by others. We felt equal, on the same level as everyone else.

The illness has made us feel vulnerable. We need to feel that you have confidence in us. Certain conditions must exist in our everyday life, just as for you also, in order for us to maintain our dignity.

- It is important for us, for those who are ill, to make our own decisions.
- It is important that one allows an ill person enough time to be able to make his/her own decisions.
- The TIME factor becomes something essential in our lives. It is necessary for us, in order to carry through our projects in a fully conscious manner, that our personal rhythm be taken into consideration.
- Unfortunately, society obliges us to follow a different rhythm from our own.
- Someone who is ill wants to make his (her) own decisions concerning his (her) course of life.
- The ill person does not want anyone else to make decisions for him (her); if one does, one is not helping him (her).
- On the contrary, by deciding for others, one binds them into the confines of their illness and puts them into a position of dependence.
- How about you: would you like others to make decisions for you?
- We who are concerned, we know when we will be needing your help.
- We are capable of accepting... or not... your offers of help and support.
- No one can think nor feel in the place of anyone else.
- It is important for us, when our illness prevents us from continuing our activities, to feel we may stop them without being judged as incapable human beings.
- We need to feel you have confidence in our capacities, otherwise we live in shame and fear.
- I think that each human being has his and her own personal dreams and desires.
- So: what is the difference between you and us?

We who are concerned by illness need your comprehension. Help us do away with barriers and open up borderlines so that we may meet one another.



Fabienne Piel

*Member of the Board of Directors of “France Alzheimer Vaucluse”
Author of the book “Afraid of Forgetting”*



POINT OF VIEW OF PROFESSOR ALEXANDER KURZ

Clinic of Psychiatry and Psychotherapy of the Technical University of Munich



Decembre 8, 2011

To the “Alzheimer Gesellschaft München”

From Professor Alexander Kurz
Head of Psychiatry and Psychotherapy

“Rencontre sans frontières – Meeting without Frontiers”
Position to apply for a grant

To my colleagues

In order to assure a good quality of life to Alzheimer patients in the early stages of their illness it is most important that their functional capacities are maintained as long as possible, that they may continue their life-style, that they participate in activities, that they remain emotionally stable and

that they keep some social contacts. Medication is necessary in the care of this illness because it helps to slowdown the progression of symptoms and to maintain the various capacities of the patient. Nevertheless, the pharmaceutical aspect must be complemented with psycho-social measures. Our French neighbors are more politically involved than we are in their efforts to improve care for Alzheimer patients.

Along with the “Plan Alzheimer” - initiated during Nicolas Sarkozy’s presidency - a variety of “pilot” structures developed to experiment with different methods of accompanying patients and their families. One example is the initiative of the “Association France Alzheimer Vaucluse” of Avignon to organize a trip to this city situated on the Rhone River. It will not only provide stimulation for Alzheimer-affected persons, thus helping to control the illness in its early stages, but it will also help promote mutual solidarity. This trip will offer to the participating patients a partial return to “normal” life, to that “normality” which is so very crucial.

With the best wishes for success in your project,

Cordially yours,
Professor Alexander Kurz



NEWSPAPER ARTICLES

Alzheimer Info



Alzheimer Info 3/12

Learning with other countries - A French-German Exchange "Rencontre sans Frontières" - "Begegnung ohne Grenzen" "Meeting Without Frontiers"

To go on a holiday trip together with one's partner - this was a wish often expressed by members of the group "Alzheimer in our lives", a group of Alzheimer patients (under 65 years) in the early stages of their illness. As most holiday offers address those who are at a more advanced stage of their illness with their families, it was decided, with the group, to elaborate a new project together.

Since three years we have been in regular contact with professionals working at "France Alzheimer Vaucluse" (Alzheimer association in Le Pontet near Avignon) in southern France. This association also works with "young" Alzheimer patients at the early stages of their illness. The idea came of organizing a meeting between French and German patients. That is how the project "Meeting without Frontiers" - "Rencontre sans Frontières"

came to life. After a good year of preparation, the trip could take place in May 2012. Seven patients with their partners and three accompanying staff members of the "Alzheimer Gesellschaft München" (Alzheimer Association of Munich) flew off to the Provence.

The week passed by very quickly, thanks to the way the stay had been prepared and organized by our French colleagues and to the variety of activities offered. Immediately after arrival we were received at the German Consulate in Marseille. The rest of our program included sightseeing tours, cooking sessions, a visit to the offices of "France Alzheimer Vaucluse" and its day care center. Musical evenings with French - German singing in a friendly, cheerful atmosphere contributed to bring relief, rest and happiness. One of the quite special events was the outing with donkeys! These donkeys, led by the patients themselves, had a "therapeutic" effect. As donkeys are not animals who "obey", it would be more exact to say they can be brought to "cooperate", a very important aspect of the outing was how touching the animals and leading them by their harness was a way to communicate with them. Patients and animals were both going at the same rhythm. "I am happy", said one person. The accompanying spouses were able to discover the energy and potential of their ill partners. They also regained courage and energy thanks to the new contacts made, and by communicating and discussing with others. Everyone appreciated the quality of the encounters, the fact that their reassuring framework allowed loosening up and communicating with one another in a free and open manner, and also the necessary space in which each person could express his/her talents. These holidays were an enriching experience from every point of view for every participating member, and definitely a positive one.

Another great success was the exchange between the two associations on a professional level. The various factors thanks to which the project could be realized gave new impetus to both sides. Language was no barrier thanks to several people among the participants and staff members who could speak both languages. The project was essentially financed by the "Glückspirale", by the Rotary Club and partially by the participants' contribution. It could only be made possible thanks to the personal investment of our French colleagues, of other volunteer participants and of several sponsors. The "exchange visit" is already in preparation for next year. Tobias BARTSCHINSKI



NEWSPAPER ARTICLES

Le Dauphiné libéré - La Provence



**Article in the local Avignon newspaper “Le Dauphiné Libéré” of Mai 21st - Le Pontet
The Alzheimer Center hosts German families**

There was an atmosphere of Franco-German holidays floating about at the “aperitif-luncheon” offered last Saturday at the Alzheimer Center “Jean Touraille”. Marie Berthet, director of the Center, Danièle Nahoum, president of the France Alzheimer Association Vaucluse, and Lisa Junglas the family consultant had prepared everything for this reception of their German counterparts from Munich.

Seven couples, each composed of an Alzheimer-ill person and his (her) accompanying partner, three staff members and a vacation trip to the Vaucluse: a way to relieve and reward those who suffer and those who, on a daily basis, accompany them and stand by them. During this week’s time, they could visit the surrounding areas and sites, go to a concert, share a meal that they had prepared together before going to listen to a jazz concert in a garden, go to a typical outdoor “provençal” market and then go to visit the brand new day Center where Alzheimer patients can find some serenity and a listening ear.

Next year it will be the turn for the French to go to Munich. The group unit is a reassuring framework inside of which the couples can feel free to communicate about other subjects. This type of initiative also shows that this disease need not be an obstacle to social life. This was an encouraging experience for both groups. It gave them the opportunity to compare experiences and thus, for the professional and volunteer workers, an opportunity to enrich their respective ways of working with Alzheimer patients, and for the vacationing families it was an occasion to make a salutary break in the - sometimes very difficult - everyday routine.



**Wednesday, 16th Mai 2012, “La Provence”, - L’Isle sur la Sorgue
Alzheimer - Normal holidays for Alzheimer Patients**

With tears in her eyes, one woman admits “ever since my husband is ill, everything has become terribly complicated. I have no energy left to organize anything at all nor to leave on holiday”. So when the French Alzheimer Association of Vaucluse and the German Alzheimer Association of Munich offered her the possibility of spending a week in Provence, she was all excited. Seven couples and four accompanying staff members are presently experiencing this wonderful adventure thanks to this

pioneer project, unique in Europe. Danièle Nahoum, France Alzheimer Vaucluse’s president and Lisa Junglas, the initiator of the project explain: “the main goal is to show them that (such an enterprise) is feasible. This illness has such a tendency to isolate people that patients and their families come to the point where they can’t even imagine trying to lead a normal life anymore”.

Creating a New Lifestyle It’s in the gorgeous, quiet “Mas Saint Damien” that the group could begin its holidays with serene reassurance. Yet their stay was very busy: reception and brunch at the German Consulate in Marseille, an outing with donkeys led by Fabienne Piel (young woman who also has Alzheimer’s and author of the book “J’ai Peur d’Oublier” - “Afraid to Forget”), a visit to Oppède, to Ménerbes, to Avignon, to the olive press and a specialized store for products of apiculture in Saint Saturnin. They also attended a classical concert, went to the outside market of L’Isle sur la Sorgue and spent a musical evening of songs with André Chiron. They spent a week filled with activities, “a real week of holidays like anyone else, beyond the boundaries of any taboos”, say Danièle and Lisa who want to demonstrate with this project that Alzheimer’s disease must not necessarily prevent patients and their partners from going beyond these limits and thus, with regained confidence, find a new lifestyle... in a natural way amongst other Alzheimer patients who are, as says the poet, “not completely different nor completely the same”. In any case, happy holidays to them, they deserve it! *Catherine CADOT*



THANKS

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- Sponsor “Glücksspirale”
- Rotary Club of Les Baux de Provence (France) and the Rotary Club of Bernau (Germany)
- Anonymous sponsors
- Liliane Touraille (founder of “France Alzheimer Vaucluse”) and Doctor Bernard Senet (co-founder) for their presence
- “Alzheimer Gesellschaft München e.V.” (Alzheimer Association of Munich)
- “Les Musicales du Lubéron” (music association of the Lubéron) for their concert tickets
- Participation by professional and non-professional volunteer helpers
- Carmen Huber for her graphic contribution in creating the programmes
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- Joseph, Tania and Nanna Kraus, Larry Ware for translations to English
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- Christian Ducroquet for his help in the local organization
- Fabienne Piel for the organization of the outing with her two donkeys “Pompom” and “Moustache” (blog: fripounette84500.skyrock.com)
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- Carolyn Ware (owner) and Dominique Demarais (employee) of the Mas Saint Damien
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- The German Consulate of Marseille for its generous welcome, in memory of Mrs. Irene Hinrichsen, consul general (died in March 2012)
- André Chiron and the musicians of the “Mistral Jazz Band”
- Michèle Sans and Martine Ruiz for preparing the “pistou soup”
- Chantal Lemaire for her interviews
- Tania Kraus for her “body workshop” under the pine trees
- Doctor Henri Nachar for his medical consultation
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- The company APP Marketing Alexander and Pusch
- The staff of AGM for their support





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Staff of professionals having participated in the project



Alzheimer Gesellschaft München e.V. (German Alzheimer Association of Munich)

Bianca Broda
Qualified social education worker
Works with the accompanying family members, creates therapeutical projects



Brigitte Fieger
Accountant, Coordinator
Works on projects



Tobias Bartschinski
Qualified social education worker
Works in the section for patients at early stages of the disease



France Alzheimer Vaucluse

Director of the day care center “Maison Jean Touraille”,
conducts a “Memory Workshop” for people with Alzheimer’s disease, music therapist



Lisa Junglas
Family counselor
In charge of “Alzheimer Ecoute”: consulting service for patients and their families



Tania Kraus
Feldenkrais practitioner, dancer, physical therapist
“Body workshop” for patients



Danièle Nahoum-Sokolowski
Psychologist
President of “France Alzheimer Vaucluse”,
psychologist at the day care center “Maison Jean Touraille”



Michèle Sans
Secretary
Coordinator, receptionist at the center



Doctor Bernard Senet
Doctor
President the day care center “Maison Jean Touraille”, co-founder of FAV

Please help us, so that confidence can replace despair.

Account for supporters

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