

## ***NEWSLETTER NR. 1 JANUARY 2004***

With 2004, we want to begin to publish a paper to inform partners and friends about all the Association's initiatives in our program. The idea is to send the newsletter out monthly or every two months, depending on the news that we will have to transmit you. We would like that this tool could become a channel of communication open to whomever will want to publish news or messages both on the association and on the world of disability. Being our first experience of this type of job, we invite everyone to collaborate and we accept gladly your suggestions both on the style and on the contents.

### **STAND FOR ST. PROSPEROUS**

On November 24, the feast day of St. Prosperous, patron of Reggio Emilia, we had a stand with the collaboration of the following volunteers : Monica R., Francesca P., Silvia F., Norberto F., Federica M., Alessandra V. and Julia, Sonia M., Stefania G., Stefania\_A., Delfina Z., who opened the sale from 8,00 am to 7,00 pm. Despite the very bad weather (fog, wind and rain), our handicraft creations were successful. We have, in fact, sold: 6 candles of gel, 14 dolls pigotte, 20 decorated vases, 5 pots with big plants, 8 bags of lavender, 5 decorated objects.

### **STAND IN NONANTOLA**

Thanks to the availability of Daniela and her cousin, we have had a stand in Nonantola from the 13<sup>th</sup> to the 21st December, in which they sold poinsettia and cyclamens.

### **CONAD CARD INITIATIVE**

Many of you know that all the supermarkets encourage their own customers with loyalty points and give them gifts at the end of the year. The Chain CONAD offers the possibility to any

association to take advantage of this opportunity. How does it work? Simple!

Each person has the possibility to donate their points, with a minimum of 500, simply by writing the number of the association, i.e. 0205006130182 on the enrolling CONAD CARD.

This initiative is happening in all the CONAD supermarkets and hypermarkets in Italy. The gifts that interest us are, obviously, computers and photographic equipment that require, unfortunately, so many points!

LET'S COUNT ON YOU!!!!

### **A CHRISTMAS OF SOLIDARITY**

Also this year like last year, Christmas has been an occasion to discover how much solidarity there is around us. There have been friends and partners that have replaced the gifts of Christmas with a donation to us, others that have purchased our merchandise, "hand made" objects and others that have made us hear their solidarity with a generous donation. Among these I would like to point out to you the initiative of the employees of Textile Diffusion, Max Mara group, that thanks to the collaboration of the dear friend Antonio Farini, has abdicated the Christmas gift assigned to them by the firm to turn it into a donation of 2.662,00 euro for our Association. Also the firms have actively participated in our harvest funds as last year.

### **BUDGET MEETING**

Within the month of February 2004 the budget meeting will be organized. We count on the presence of all the partners. We will explain the budget and will also tell you about the meeting of last November 2003 among the members of the CD and the CS and the projects that will start in 2004

## ORCHESTRA OF "MONTE CUSNA" CHOIR

Many of you were present last 24 October at Valli Theater in Reggio Emilia at the concert of the Choir Monte CUSNA whose takings have been given to our association. The concert was very beautiful and succeeded in filling the Theatre up to the galleries! Beyond the money collection, it was a big opportunity to introduce the association to an audience of around 1.000 people. Over the following days, we received a phone call from a family of Lecce who had a child with the 14q deletion, since one cousin of theirs was present at the concert and he had told them about us!

## WORKING OFFICE

Our waiting has been worthwhile!  
The Health Directorate of the Hospital Santa Maria Nuova in Reggio Emilia has given us a room in the Operational Unity of Infantile Neuropsychiatry on the 3° floor of the central block where the NPI already has the clinic of the Day Hospital. The Health Directorate has also granted our Association, in accordance with the Complex Structure of Infantile Neuropsychiatry, the possibility to share with them a space that we will use as working office, without interfering, naturally, with their medical activities. This space offers us the possibility to organize turns of job schedules for all the volunteers that will want help us. The office will be open from the month of February 2004. People interested to help us can already put in contact with Stefania Azzali to arrange their turns and the type of job to develop.

## DONATION OF EMG + EVOKED POTENTIAL

Since last February, our Association, in collaboration with the Coordination of the Elderly Social Centres of Reggio Emilia, was activated for giving a useful tool to the Unity of Childish Neuropsychiatry of Reggio Emilia. It is a very important tool in the study of the RING14 syndrome, as well as in the study of other chromosomal syndromes. The electromicrograph is important for the study of the nervous system, both central and peripheral to the same degree, since it allows appraisals, correlated to other radiological investigations and of laboratory, the causes and the

mechanisms of the symptoms and neurological signs of the children with chromosomal illness, such as hypotonia, visual defects, auditory, cognitive and motors. Inside the Complex Structure of Infantile Neuropsychiatry there is now the necessary medical competence to use the instrument specifically during childhood years. And it is really this specificity of using the EMG in children that will make the department very important in the regional and national field. Such a tool will be given during an official ceremony and press conference on the 28 February 04 Saturday. I want to underline the great collaboration given us by Social Centres picking up the whole necessary amount to purchase this machinery for a total of 15.000,00 Euro. We are really proud to have collaborated to realise this first important project for RING14 children and for all children with illnesses of the nervous system.

## HAND-MADE CRAFTS & DECOUPAGE

The hand-made crafts evening in January will be held in the Azzali's house because, with the Christmas gifts and the stands, we have practically sold out everything! I want to send a Big Thank You to everyone who has helped us with their presence and "hard work", brightened however by so much chattering and by some sweets... particularly I want to thank Silvia and Stefania Gatti who with their mother Ivana, had given a fundamental contribution to the realization of beautiful dolls pigotte (all sold!), Monica Russo and Sandra Prati for the "decoupage department". Here is the Calendar 2004 up to easter:  
JANUARY: 14 Wednesday, 26 Monday  
FEBRUARY: 10 Tuesday, 25 Wednesday  
MARCH: 9 Tuesday, 22 Monday  
APRIL: 7 Wednesday

## OUR INITIATIVES IN 2004

We are still in the organizational phase but we can anticipate that surely the hand-made crafts evenings will continue, there will be a "cultural" dinner for collecting money and very probably also a cabaret show and another concert at theatre.

We will be more precise in the next newsletter !!

## I INTRODUCE YOU TO MISS

### ROSA

The Services Centre DAR VOCE, of which we are partners, has been pursuing from last year the project to sensitize young people of the higher schools of Reggio Emilia and Province on the theme of the voluntary service. The project developed in 3 phases. The first phase was an approach to the world of the volunteering and the variety of themes touched, the second phase developed a simulation of the various themes as an orientation to the young people based on their preferences and attitudes while the third phase is operational and foresees the integration of the youngsters inside an association for a minimum period of 6 months. I had given the availability of our Association to welcome young people interested in developing a job of reception office near our association. Also here luck has helped us: during the party of St. Prosperous, Rosa found our stand and she was immediately interested in us. Rosa is one of the girls who have completed training with DAR VOCE and she was waiting to be placed as a volunteer inside an association. Her interest in us is also tied to the fact that Rosa knows carriers of a rare genetic syndrome, Fragile X, and she wanted therefore to look for an association that dealt with this type of problem. She has found us and we have found her! She will begin work in February 2004, but she is already helping us with translations because, another stroke of luck, she studies languages!!!

### CIVIL VOLUNTEER

We are always searching for girls available to complete with us one year of Civil Voluntary stage. There are two calls each year and therefore we always appraise the applications. The fundamental requirements are:

- to be an Italian citizen;
- to enjoy civil rights and politics;
- not to have had penal sentences pre-meditated crimes;
- to be physically fit, certified by the national health service, with reference to the specific sector of employment for which he intends to compete.
- age from 18 to 26 years old
- The total schedule is 1200 hours in 12 months.

Volunteers in civil service are paid by the Italian government €433, 82 per month less a fiscal retention of 18%. In ours specifically:  
Weekly schedule: around 24 hours from Monday to Friday, exceptional initiatives excepted (e.g.. banquets or events for collecting money that could take place at the weekend or in the evening.  
Place of work: mainly the operational centre of the association in the office in the hospital of Reggio Emilia, otherwise in the legal centre in 34 Hugo Street Reggio Emilia.  
Requisite: good knowledge of English, better even if have French, good use of the PC, studies in medical field (optional), better if car provided.  
Type of job: in the reception office and not helping with children.

### CHILDREN WITH RING14 & 14q

They are rare, it's true, but that rare!  
Do you want some numbers? Here they are  
40 Families with RING 14  
22 Families with 14q  
Of which:  
7 Italians , 34 Americans, 5 Australians  
5 Canadians, 4 English, 1 French, 1 Norwegian,  
1 Israeli, 1 German, 1 from Mozambique,  
1 from New Zealand, 1 from South Africa.

### UPDATING THE WEB

As you know every month we amend our web site. During the last two months:  
We have included the facility to download Acrobat software from our Home Page  
Italian Version  
RASSEGNA STAMPA: we have included 9 articles gone out among Oct and Nov. 2003  
LE NOSTRE INIZIATIVE we have included the brief meeting of the Congress on rare illnesses in Paris + 2 poster.  
I NOSTRI PARTNERS: included the logo of Coordination of Social Centre and the logo of Choir Monte Cusna  
LINKS: included links to AIDWEB  
English Version  
OUR CHILDREN'S HISTORIES we have included the first part of Matteo Russo  
French version  
OUR CHILDREN'S HISTORIES: included the history of Eli - FORUM: Translated everything

## **DAR VOCE: SPORT PROJECT**

During 2003 the Services Centre DAR VOCE has organized a series of meetings among the associations, separated for topics, with the objective of making projects to be realized during 2004. We participated in the working group about disability and we have decided to work within the inclusion of our children and boys on the sports field. As our city is well equipped and organized, thanks to the contribution of the local corporate body but also to the big appointment of we associations and social cooperatives, for all of this that concerns the rehabilitation, the problems are born when a less able boy want to take part in sports for able youngsters. The most difficult difference is that the more able children approach the sport in a competitive way. This often becomes an insurmountable obstacle for all of our boys who are not so involved and they stay excluded, creating in them dissatisfaction and frustration. The objective of our project is to organize an event in which city, schools, teams and our children and boys with disability meet for one or more days playing different sports all together. Both meetings and debates will be organized with the authorities and all the people and corporation involved trying to find concrete and effective solutions in an important sector for everybody.

A beautiful challenge isn't it?

## **LIONS CLUB AND CHILDREN HELP RING14**

It is always beautiful and important to speak about solidarity, but this concept assumes even more importance when the theme is developed by the children for others' children.

Just in our city of Reggio Emilia a marvellous project has been effected, between the children of the section four years of the school of the infancy Paulo Freire, and Lions Club in favour of our Association. The promoter of this initiative is the Lions Club Reggio Emilia Host, that, on the occasion of the gala dinner of the opening of the year last 24 October 2003 thought to develop a "service" for the association RING14. The Lions Club of Reggio Emilia and Province, have been already been supporting the association over the last year and they will continue during 2004 through initiatives of raising money and publicising the association. The initial idea of the Club was to

devolve the expense related to the floral decorations of the tables for the evening, to the association, a gesture already of great value for solidarity, that subsequently developed into the idea of involving the children in this project and particularly the children of the 4<sup>th</sup> year of the Paulo Freire Infant School, the year frequented by a child with RING14 syndrome. The initiative has been arranged with the teachers and pedagogist of the Paulo Freire school, that in coherence with the principles and the educational values of infant schools in Reggio Emilia, have appeared very sensitive and participate above all in the theme of the solidarity to the children. The Idea has been translated into a concrete possibility; the children have immediately begun to try to make some objects by the development and elaborations of iron sculptures of leaves (theme already crossed by the children during the passage of the seasons), then decorated and embellished with objects of various type, coral, clippings and other recycled material. The sculptures have been therefore put into the middle of each table for the gala dinner of the Lions Club Reggio Host, accompanied by the brochures of the association RING14 and, in accord with the direction of the school, put on sale for the association RING14.

The collaboration with the school is not limited to the production of these beautiful objects by the children, but has become the possibility and occasion for introducing the theme of the solidarity and respect for one another and of differences, in the section and in the school, soliciting a dialogue and comparison participated among children, teachers and parents. "Our leaves the mother Stefania puts her to the centre of the tables to a party and then they bring her in a place to sell for having the money to recover her children"

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