

# No. 3 NEWSLETTER DECEMBER 2004

## FINANCED PROJECTS

### GENETIC RESEARCH DOCTORATE

The genetic molecular research doctorate by Catholic University in Rome began the last April is proceeding well. Thanks to all families, not only in Italy but in the world, who are doing their best to collaborate sending champions of blood needed to this very important study. We won't wait too much for the results!

We take the opportunity even to press all families who haven't collaborate yet but they desire to do it, to enter in contact as soon as possible with our office to plan sending champions of blood.

### RING 14 FAMILIES AND 14 DELETIONS

With a slow rate we continue to increase.

Now we are 79 families of which:

52 with ring 14

27 with chromosome 14 deletion

Of these: 8 are Italian, 10 are European, 51 are American (USA) and Canadian, 10 of other nations.

## SOLIDARITY INITIATIVES

### GREETINGS CARDS

We have the possibility to print Christmas greetings cards even personalized (for firms), to the cost of 0,80 €each one. For booking or buys please contact the association via e-mail or by phone.

### 28<sup>TH</sup> JULY: FEAST FOR THE SARAWI'S CHILDREN

Inside of the meeting on Handicap organized by "DAR VOCE" services centre even our Association represented by Andrea Russo, has collaborated to the organization and to the realization of this moment of welcome for Sarawi's children. The feast took place on 28<sup>th</sup> July in San Prospero square in Reggio Emilia. After the welcome from the town authorities in Italian Flag Room, the feast went on in the square with stalls and animation initiatives organized by "CreativEducare" and "V.I.P. Viviamo In Positivo" groups.

## SOLIDARITY STALLS

Thanks to members and volunteers availability we were able to be present to the following manifestations:

17<sup>th</sup> and 25<sup>th</sup> July in Nonantola: thanks to Daniela!

4<sup>th</sup> September in Giareda feast of Ghiara Lady in Reggio Emilia: thanks to Stefania and Monica!

## NEXT STALLS

Nonantola: 21th and 22th November

Reggio Emilia: 24<sup>th</sup> November for San Prospero feast, our stall will be near Teatro Municipale in “della Vittoria” square. Who wants to profit for buying some Christmas presents will find: decoupage pots, rag dolls, gel candles and little chalk pictures.

## PARTICIPATE!

### 19<sup>TH</sup> JUNE: MARIA SILVIA AND ALESSANDRO’S MARRIAGE

A gesture of big generosity the one realized by Gatti Maria Silvia and Bonini Alessandro that in the occasion of their marriage thought to devolve in charity to Ring 14 Association the amount usually assigned to bonbonnières involving and sensitizing in that way all their friends and relatives who have appreciated and liked this gesture of great generosity and solidarity. Silvia is also actively engaged in the Bricolage Project of our Association, many of the dolls for sale on our stalls goes out from her hands and from her mother Ivana ones.

The collected money, were put in a fund instituted for scientific research and will be assigned to financing research projects in medical and scientific field coordinated by the Association Scientific Committee.

## BRICOLAGE EVENINGS

All stalls we were able to prepare during the year (and they were really a lot!) were possible by the availability of a lot of friends who participated with faithfulness and enthusiasm to our evenings, making possible the realization of a great number of objects (decoupage pots, gel candles, rag dolls) then sold with success in stalls.

But evenings are not only work....between a stroke of the brush and the hem of a little cloth, the cutting of a flower and the choice of a color, consolidated friends are born, chains of solidarity were created.

Children illnesses leave heavy marks in the hart of all people! Many thanks to all people who goes on to collaborate to this beautiful project, we’ll inform you about future dates.

## DIVULGATION INITIATIVES

### 18<sup>TH</sup> JUNE:LIONS HOST DINNER

The Lions Host Club of Reggio Emilia invited our President to their end year closing evening. During the evening Dr. Mastronardi, Lions Host President delivered to Mrs. Azzali the offer made from doilies realized by children for their opening evening that took place on 24<sup>th</sup> October 2003 (see newsletter No. 1)

### 25<sup>TH</sup> JUNE: YOUNG INDUSTRIALISTS DINNER

Thanks to the availability of young industrialists President Dr. Gherpelli Cristina gave us the opportunity to present our association during the evening organized for their members.

### 22<sup>ND</sup> SEPTEMBER: SOLIDARITY AND SPORT: WINNING COUPLE

Unforgettable the evening of last 22<sup>nd</sup> September in Palabigi: first Bipop exit in town after the extraordinary last championship. The wait for this appointment was still greater as together with this we celebrated thirtieth anniversary of foundation of basketball of Reggio Emilia and the promise for many generation sporting men, to see again all together the dear protagonists of near and far emotions. For the occasion it was organized a luxury friendly match versus Fortitudo Bologna, and the whole town basket team wanted to show its own nearness to the solidarity values, devolving the whole evening taking to Ring 14 Association and to Reggio Emilia UILDM section. For the record, the result was 94 to 60 in favour of Bipop Reggio Emilia. It was very beautiful to see Palasport crowded, to see the parade of various players: Codeluppi, Rustichelli, Montecchi, Marcelletti and to hear the burst of applause for the big Mike Mitchell( yes, there was even him!), without naturally to forget the opposing champions of Fortitudo, with the Olympic players Basile and Pozzecco, knowing that, in addition to the passion for sport, there was also the attention for persons with an handicap.

During the 22<sup>nd</sup> October evening, in occasion of the championship match between Bipop and Fortitudo (again them!) the Ring 14 Association and the Reggio Emilia UILDM section received the contribute made from the thirty-year match, which amount to twelve thousands euro. We saw that two so different strengths but both moved by the confidence in its owns means, can do great things. And many thanks to Bipop's President Stefano Landi, for his great sympathy and for his true interest in our demands. Thank you again Mr. President and we hope to meet you again.

## PARTICIPATION TO MEETINGS

In the month of October we participated to:

INTERNATIONAL MEETING: "RARE ILLNESSES AND ORPHAN MEDICINES: A GLOBAL RIGHT TO HEALTH" held in Rome from 13<sup>th</sup> to 15<sup>th</sup> October.

In behalf of the association the President Stefania Azzali participated. The presentation of Association and of research projects will be enclosed in the meeting acts.

MEETING: "RARE ILLNESSES AND VISIBILITY: HOW TO ACCOMPLISH A STRATEGY OF EFFECTIVE COMMUNICATION" held in Milan, on 22<sup>nd</sup> October.  
In behalf of Association Dr. Giustardi Annamaria participated.

7<sup>TH</sup> ANNUAL NATIONAL MEETING OF ITALIAN HUMAN GENETIC SOCIETY (SIGU) held in Pisa from 13<sup>th</sup> to 15<sup>th</sup> October 2004.  
The members of our scientific committee, Prof. Neri, Prof. Zollino and Dr. Mattarelli presented an abstract, published in the meeting posters, relative to the done studies on Ring 14 financed by ourselves.

In addition it is foreseen our presence in Bologna, on 19<sup>th</sup> November at "GENETIC MEDICINE DAY".

Besides the formative opportunities these days offer, they are fundamental occasions to increase our visibility and to know other realities, in the field of rare illnesses developing from one month to another. Our impression is that medicine is progressively beginning to be more interested in rare illnesses, and we are seeing that more often the various associations (that for the most part are formed by parents that is people "suffering" the reality of rare illness, they don't study it) are involved by authorized persons in the context of scientific initiatives.

#### WEB SITE UPDATING

In consideration of numerous arguments now treated in the site, for a greater ease of reading, we grouped the arguments and created under-categories that you can find organized in the new key "site-map". The updated arguments are:

In the Italian version we inserted new links, articles in the press report and stories of new children in the password protected area. Inside the key relative to medical and scientific research we inserted the research project with practical details for the sending of blood samples.

Even in the English and French version, thanks to the works of many volunteers, we are proceeding in the text's translation.

**WE ARE LOOKING FOR OTHER VOLUNTEERS FREE TO HELP US IN  
FRENCH/ENGLISH/GERMAN AND ALSO SPANISH TRANSLATIONS.  
LET'S CONTACT US!!!**

#### YEAR 2004 MEMBERSHIP FEES

We remind to our members who haven't yet balanced the annual fee to do it within the month of December. The missing payment of the fee involves the exclusion from the associative activities.

**ORDINARY MEMBERSHIP FEE 50,00 EURO  
ASSOCIATED MEMBERSHIP FEE 30,00 EURO**

With the associated card, it is possible to enter of the association with full rights, but without the obligation of participation at society and steering organisms, thing that, on the contrary, the

ordinary members are obliged to. Who wants to become an ordinary member must do a writing request (letter or e-mail) to the Association before. The relative payments must be done on the current account of the Association, which elements are reported at the foot, specifying Name, Surname and type of card.

## WHO WANTS TO SUPPORT ECONOMICALLY OUR PROJECTS

Can do it with a free payment to send to:

UNICREDIT BANCA SPA  
COUNTRY: IT – CIN EUR 27 - CIN H – ABI 02008 – CAB 12820  
CURRENT ACCOUNT N° 3665310–headed to  
“ASSOCIAZIONE INTERNAZIONALE RING 14”

The international association of volunteers Ring 14, is registered to regional register of volunteer organization, according to the Italian law 266/91, dated 2<sup>nd</sup> September 2002 n°68266, and also ONLUS (non profit-making organization), according to article 10 chapter 8 of decree with the force of law 460/97. Therefore the donations can be deducted according to the limits and to the article 13-bis of President decree 917/86, if the paying subject is a natural person or non commercial agency, or can be deducted according to the article 65 of President decree 917/86, if the paying subject practices an enterprise activity. These amounts will be in any case assigned exclusively to pursuing the institutional aims of volunteers association. Who wants to receive the receipt for the fiscal deduction must send us a request via e-mail or letter.

DO YOU WANT TO RECEIVE THE NEXT NEWSLETTERS? REGISTER YOU IN OUR SITE  
[www.ring14.com](http://www.ring14.com)

WE TAKE THE OPPORTUNITY TO WISH YOU MERRY CHRISTMAS  
AND HAPPY NEW YEAR!