

JANUARY-MARCH 2008

BALANCE MEETING

The annual balance meeting will take place on Saturday, April 5th 2008 at the Service Center "Dar Voce" of Reggio Emilia from 9.00 a.m. to 12.30 p.m. approx. The agenda will be :

- analysis of the balance of the year 2007
- renewal of the council charge
- development of the scientific projects
- initiatives of fund collection
- congress 2008
- various and eventual subjects

OUR CHILDREN

BIRTHDAYS

Unfortunately, as already reported in previous news-letters, we don't know the D.O.B. of all our children, we invite the families to inform us the D.O.B. of their children.

In January, February and March we had the following birthdays:

CARRAZEDO	REECE	13 jan 1998	SOUTH AFRICA	Aacarra@global.co.za
Estes	Heather Lynn	17 jan 1988	U.S.A.	EstesDH@juno.com Tom.ferguson@worldnet.att.net sferguson3@cox.net oksferguson@msn.com
Ferguson	Costillo Brooke	21 JAN 1992	U.S.A.	Sunshine59@earthlink.net t.Vibeke@taktekkern.com
FIFE Laura	Hailey	06/02/01	U.S.A.	mr_g@blueyonder.co.uk
BERNSTEN	Celine	18/02/00	NORWAY GREAT BRITAIN	Swelstars@aol.com
Grimes	AMY	18/02/93	UK	_d_arcy@hotmail.com
CARANTO	DAVID	18702/94	U.S.A.	ROMAKO@aol.com
EDISON	Timoty	27/02702	U.S.A.	Jane@diesel1.demon.co.uk
WRIGHT	VAUGHN	04/09/1992	UK	k-kwhiteley@tesco.net
Kovacik	Alexandria	03/03/1995	U.S.A.	Liffigirl@aol.com
Whiteley	Paul	06/03/1970	UK	Jemar@bigpond.com.au
LIFFEN		12/03/1998	UK	did.isa@wanadoo.fr
ROBINSON	ADRIA	25/03/1999	AUSTRALIA	
BABIN	Romain	27/03/1997	FRANCE	
Russo	Matteo	30/03/1999	ITALY	Info@ring14.it

OUR BEST WISHES TO ALL OF YOU!!

In the past three months we got in contact with five new families:

BRARD LAURENT (Partial trisomy14)- Giberville, Francia

BINETTI TERESA with Federico (Ring14)- Bisceglie, Italia

MURDOCK CAROLINE & ROBERT (Ring14)

RAYMOND A CLOSE with Livvy (Ring14)- Australia

FALCON TERESA (Ring14)- Maimi,USA

Welcome!!!!!!!!!!

AFTER THEM

Often the subject of discussion is "AFTER US", that is to say: who will take care of our sons when we will be not anylonger with them, but seldom the subject in discussion is "AFTER THEM", because it is too hard to take into consideration a future without our children. Sometimes, however, that arrives; it is unavoidable, sometimes it's life, sometimes it's owing to the disease.

In the last months our little friends Maicol and Lorenzo left us. It's difficult to find the right words in a so sorrowful moment, that's why we report a thought from a newsletter of FACE Association (Association of families of cerebroinjured persons) of Reggio Emilia, written by Carlo and Nikki in memory of their son Lorenzo:

CARLO: The day after Lorenzo's death, July 2000, a newsman asked me: "I think now you will not work anylonger for the Association (Carlo was the President of FACE)"

What a stupid question! Our life is difficult, complicated, but it is not made only of pain and disease. Where is happiness lived with my son? The joy, the closeness and the deep emotions shared with him How could the parents and the associations to convey love, happy sensations and joy to all persons who don't enjoy those feelings? Often people think to us as families living only in pain, what have we to do for stopping that stereotype? It is important that an Association knows how to deal the death theme, silence does not help the families to face their sorrow! Lorenzo's joy was an inward happiness, Let us hear it and let us learn from it. His smile, his living joy will remain after him!

NIKKI: If we look at the life with different eyes, valuing it as a gift, we will approach the real sense of life since love goes over handicap... What is therefore the sense of our life? We gave life to him and he made life a gift. May be it's difficult to say "after him" that's why we could say "always with him" because his life is still here with us. It's just his life which allows us to live after his death. His life was, is pure love!

The question is not "why he died", Pennac said that things don't explain themselves by their cause, but by their consequence; if a child ask us: "why is it raining?" We must not answer "owing to bad weather, to clouds" but we must tell him that "it's raining since thanks to the rain many flowers will grow!" and Lorenzo made a lot of flowers growing....

There is at last a noble deed that families could achieve for helping the research and the other children: to authorize, in case of death, the drawing of small samples of brain material. We know how hard would be to speak about that subject when facing the tragedy of a son's death; it's just for that reason that we prefer to deal that subject now, generally speaking, so that available families could evaluate and take their decisions acting in cold blood. Don't hesitate to contact us for any further information or explanation.

OUR PROJECTS

2nd International Congress RING14 Association

Our second congress will take place on **25th-26th-27th September 2008 in Reggio Emilia.**

The first day, Sept.25th, will be reserved to the workshop A.B.A. Applied Behaviour Analysis which will offer a theoretical and practical introduction to the use of A.B.A. principles for the teaching to persons with language and knowledge delay, problems of the autistic spectrum and problem behaviours.

The A.B.A. workshop will take place at the International Center Loris Malaguzzi.

The second day, at Hotel Astoria, will be reserved to the scientific congress "Medicl Research and Patient Care"; during the third and last day, Sept. 27th, our scientific doctors and researchers will carry on observations and medical visits of our children with a following ronde table among families, scientific committee and researchers.

At the same time of congress development, for all the three days of congress and in both the congress seats, it will be operative a playing room where the children will be entertained by our voluntary assistants.

The detailed program is going to be sent and families have been informed of the decision, taken by the Board of Direction, to charge the Association with the cost of board and lodging of the participating families in order to allow more families to attend the congress.

We invite therefore all families to let us have their adhesion after receipt of the program under despatch.

WE ARE LOOKING FOR: SPONSORS AVAILABLE TO HELP US IN SUPPORTING ORGANISING EXPENSES AND COSTS FOR BOARD AND LODGING OF THE FAMILIES; VOLUNTARY ASSISTANTS FOR THE PLAYING ROOM AND FOR SECRETARIAT; ASSOCIATIONS, CLUBS, RESTAURANTS, CONFECTIONER'S AVAILABLE TO OFFER US COFFE-BREAKS AND DINNERS.

[Programm of the congress](#)

[Letter for families](#)

GENETIC PROJECT

Dr. Laura Seminara has finished the triennial doctorate assigned by the Catholic University of Rome. The Association wishes to thank heartily Miss Dr. Seminara for the passion, professionalism and devotion to the research foreseen by the doctorate and for her availability in collaborating with everybody.

Thanks to the authorization kindly given by Catholic University it is possible to find Dr. Seminara's thesis in our web site at the following address: <http://www.ring14.org/ricerca.php?id=4>

Our warmest thanks to Dr. Laura Seminara wishing her a future rich in other opportunities of prosecution of the studies carried on with a so great care, passion and real turn.

We report herefollowing Dr. Seminara's greetings: "I also wish to thank by heart families, members and colleagues for the affection and availability reserved to me. I must say that working with you has been a very important professional experience, but firstly a great personal experience. I hope my work will contribute to make a forward step in the study and comprehension of that syndrome and will allow a smile more to the families of those special children. Once again many thanks to everybody.

For the year 2008 the Association, in collaboration with the Cytogenetic and Molecular Cytogenetic Laboratory of Sacred Heart Catholic University of Rome, responsible person Prof. Marcella Zollino, assigned a study prize to Dr. Orteschi Daniela who is charged to carry on the cytogenetic analysis through array-CGH technique. We take this opportunity to welcome Dr. Orteschi wishing her

research started by Dr. Seminara, always under the careful
es on the great importance of collaborating actively
in that innovating project by sending their blood samples to the Laboratory of Rome
following instructions reported in our web site
<http://www.ring14.org/progetti.php?id=1> or contacting our seat.

DATA-BASE AND CLINIC PROJECT

Many thanks to all the families who have actively collaborated by sending the questionnaires and the medical documentation while, at the same time, we invite families who have not yet sent them to provide promptly.

We know it takes time and labour but thanks to that project we are collecting very useful informations on those syndromes which will be presented and discussed during next congress of September.

Particularly as far as rare diseases are concerned, family collaboration is basic to allow doctors to collect quickly the most of useful information. Time, our family well know, is precious for our children!

We thank MANODORI FOUNDATION for contribution given to that important project through the co-financing of a scholarship for Dr. Scarano, neuropsychiatrist and researcher for our association.

OPENING OF FOREIGN SEATS

The pening of the French seat is very near. Families, coordinated by Mrs. Emmanuelle Della Monica, are going to have Statute ready.

As to Great Britain, Mrs. Lisa Jones charged herself as local referent person.

In order to facilitate their work and to make our web site more visible in tehir contries, too we have bought the domains .fr and .co.uk and created their mail address of the association as reported herebelow:

For France: contact person Della Monica Emmanuelle: ring14-france@ring14.fr

For U.K. : contact person Jones Lisa: : ring14-greatbritain@ring14.co.uk

PROJECT OF STUDY OF THE LANGUAGE AND ASSISTANCE TO THE FAMILIES:

Dr. Paola Martinelli is completing the visits to the Italian families. The results of that study will be illustrated during our 2nd Congress on the month of September.

On the base of evaluations carried on our children in developing that project we have addressed the research also to the analysis of possible behaviours pertaining the autistic spectrum with the target to give the most of information and useful suggestions about the more efficacious rehabilitating methods for our children.

We are furthermore happy to inform you that Dr. Paola Martinelli, who has been developing an excellent work for our association for two years, has been engaged full-time for the next two years.

Further to the engagements already under development she will be COORDINATOR AND RESPONSIBLE FOR ALL OUR PROJECTS and a part of her time will be also reserved to the assistance and psychological support of families applying to the RARE DISEASES CENTER which will be illustrated herbelow.

"NEUROMETABOLIC AND GENETIC RARE DISEASES CENTER" PROJECT at Santa Maria Nuova Hospital of Reggio Emilia

It is a local project we accepted to support in order to let our Italian seat and our researchers make part of a regional and national referring center officially acknowledged.

with the purchase of a gaschromatograph.

DI COMPANY we have been able to renew for the second

subsequent year the complete financing of a scholarship for a doctor specialized in children's neuropsychiatry, assigned to Dr. Frattini Daniele.

Thanks to the funds of the firm MARIELLA BURANI we shall be able to guarantee, for next two years, psycologic assistance to the families relating to the Center, given by our psychologist Dr. Paola Martinelli.

Diagnoses of those diseases are devastating for families and unfortunately psycologic support, which could help them, is often undervalued or ignored. We shall try, through Dr. Palola Martinelli's assistance, to help families to overcome that difficult moment.

EVENTS FOR POPULARIZATION AND FUNDS COLLECTION

"LIFFI" BENEFIT DINNER

On January 18th it took place, at the seat of the òLiffiö Gang, a benefit fish dinner with 82 participants. We thank the President of òLiffiö Gang, Mr. Pietro Scapinelli and the many voluntary assistants who made possible the realization of that pleasant culinary event.

SERVICE LIONS CLUB CANOSSA VAL D'ENZA

On February 8th, during the intermeeting organised by the Lions Club Canossa Val d'Enza, at the presence of numerous Lions Clubs of the town as well as of the President of Manodori Foundation, Dr. Antonella Spaggiari, our Association received a generous grant of Euro 11.650,00. Those funds were collected through a Charity Pinnacolo of last November with the generous contribution of CONAD ALBINEA and the annual service of the Club and have been destined to our clinical projects.

SERVICE INTERACT

Teen-agers of Interact Club of Reggio Emilia, under Bellotti Elisa's presidency, organised on the occasion of Epiphany holiday a special sale of cakes at the Tennis Club of Reggio Emilia granting the collected amount also to our Association. The event was preceded by an interesting meeting in which our Association illustrated its targets to the teen-agers.

MUSICAL PERFORMANCE

It took place, at the Massimo Troisi Theatre of Nonantola, the musical SHRECK- organised by TEATROVENTUNO with proceeds devoted to our Association.

Many thanks to our member Mrs. Bruni Daniela for giving us that opportunity.

MONEY-BOXES

The Association bought small terra cotta money-boxes to be distributed to shops and stores. Thanks to the collaboration of some social cooperatives and Day-care Centers of Reggio Emilia and province they will be decorated with our logo. We shall provide shortly to send some money-boxes to the Italian families making part of the Association so that they might distribute them to their usual stores (bakery, butcher's shop, laundry etc.) It's useless to say that the project is open also



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laborate; therefore don't hesitate to contact us! For the time
y in Italy.

CHARITY STANDS

In the near future we are going to be present :

April 12th at Nonantola (MO) 12 aprile a Nonantola (MO)

April 17th – from 9.00 a.m. to 5.00 p.m. in the hall of Santa Maria Nuova Hospital – Reggio Emilia

May 15th – from 9.00 a.m. to 5.00 p.m. in the hall of Santa Maria Nuova Hospital - Reggio Emilia

As usual, we are looking for voluntary assistants able to cover the turns.

Visit us! We wait for you!

FEAST OF CANALI PARK

On Friday, May 31st there will be the fest of CANALI quarter (RE) where is the seat of our Association. We will be there with a stand for popularization and fund collection. WE ARE LOOKING FOR VOLUNTEERS!!!!!!

CALENDARS: we have still on sale our calendars for 2008 at the price of Euro 8,00 each.

You will find a facsimile in our [link](#) site.

Many thanks to all Italian and foreign families for the collaboration given in that initiative of popularization and fund collection which has really given positive results.

BENEFIT DINNER: a friend and member of Lions Club Canossa Val d'Enza is organising, for the month of May, a benefit dinner with show in our favour at the CERE CLUB of Reggio Emilia. We shall give you more information in the coming days.

1ST EUROPEAN DAY ON RARE DISEASES

On February 29th it has been celebrated the 1st European day on rare diseases.

The date of February 29th has been proposed by the European Organisation for Rare Diseases [EURORDIS](#), just considering that February 29th arrives only every four years and therefore well represents the concept of rarity even if in the future it will become an annual event.

Our association organised on that occasion a stand for popularization and fund collection at the Conad store of Albinea in the days of February 29th and March 1st.

Many thanks to Conad store management and particularly to Mr. Cristian and the voluntary assistants who allowed to carry on that initiative.

[FEDERMARE Press notice](#)

[European day on Rare Diseases](#) from Gazzetta di Reggio (27th february 2008)

5 X 1000: DESTINING TO US YOUR 5 X1000 YOU WILL HELP US WITHOUT PAYING NOTHING

The financing act 2008 confirmed the possibility of destining an amount corresponding to the 5x1000 of the income-tax of physical persons for supporting ONLUS (income-tax declaration for 2007)

Your choice will not modify the taxes to pay and will not replace your choice for 8x1000 which remains still in force.

You can make your choice in favour of International Association RING14 for the Research on Neurogenetic Rare Diseases by signing in the specific area of the income-tax declaration "support for no-profit organisations with social utility..." And by indicating the fiscal code of the

Associazione Ring 14: 91105800352

Many thanks in advance to all of you who will support us .

PRESS REVIEW

Up-dating at the [link](#)

WE HEARTILY THANK FOR THEIR GRANTS IN FAVOUR OF OUR ASSOCIATION:

Elisa Barbolini and Laura Ferrari who renounced their birthday presents
The firm BERTANI for the advertising stripe free of charge
Domenico and Fiorentina for the charity bombonnières of their marriage
Giorgia Ferretti for the charity bombonnières of Alba's Holy Communion
Nuova Planetario on the occasion of the Women's day
Radman Sergio
Class IV B primary school
Chilloni Linda for purchasing our calendars
Bruni Daniela in memory of aunt Chloe.

FURTHER INFORMATION

EMAIL RE-ESTABLISHMENT: passage to a new server has been completed, therefore all email addresses of the association are now operative, in detail:

info@ring14.it it arrives to the seat of the Association
presidenza@ring14.it it arrives to Stefania Azzali
martinelli.paola@ring14.it it arrives to Dr. Paola Martinelli
mazzi.lorenza@ring14.it it arrives to Lorenza Mazzi

We inform you at last that it has been constituted in Reggio Emilia the **Provincial Committee of families and friends of disable children with the following main targets:**

- a) To press the Regional Sanitary Service and AUSL to entirely apply the Guide Lines foreseen in the dossier 103/2004: "Assistance to persons affected with diseases of the autistic spectrum" particularly as regards the hours per week reserved to the therapeutic intervention, fixed in the document in 20 hours minimum per week.
- b) To check that AUSL, as indicated by the City Council, starts already from 2008 the specific training of ABA operators with attested professional experts internationally acknowledged activating at the same time the collaboration for the therapeutic practice with private professional experts according to what foreseen by the Regional Sanitary System.
- c) To guarantee families already applying that method the therapeutic continuity with their experts whose work will be refunded by AUSL as the mayor declared in the City council.

For further information don't hesitate to contact directly Stefania Azzali: info@ring14.it

ASMME PUBLICATION

Cometa ASMME Associazione Studio Malattie Metaboliche Ereditarie (Association Study Metabolic Hereditary Diseases) <http://www.cometaasmme.org> realized in collaboration with our Association, in the person of Dr. Paola Martinelli, a publication titled [UNA FAMIGLIA...UNA STORIA](#).(A family.... A history)

That publication has the aim to help parents facing every day all problems and doubts concerning their sons' care.

'Every family has its own "unique" history, but comparing itself with other different realities might take better consciousness of its situation, getting stronger, recovering confidence , **realizing to be no more alone**'



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receiving a copy of the publication contact by mail:

MEMBERSHIP SUBSCRIPTION: also for 2008 the membership subscription will be of Euro 50,00 per family; we invite who has not yet provided to make subscription indicating his family name and specifying "membership subscription family"

HOW TO SUPPORT OUR ASSOCIATION:

- By a voluntary gift to be sent to: **DEUTSCHE BANK IBAM: IT 46 C 03104 12800 820369 HEADED TO 'ASSOCIAZIONE INTERNAZIONALE RING14'**, Or by credit card directly through our web site. Grants can be deducted from income-tax declaration.
- By destining the **5 X 1000** when drawing up your income-tax declaration making your choice in the specific area "support to no-profit organisations of social utility" Indicating the fiscal code of Associazione Ring 14: 91105800352
- By purchasing our BENEFIT BOMBONNIERES in case of marriages, holy communions and baptisms.
- By grants in memory of
- By purchasing our objects from our charity stands or directly from our web site

For information:

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