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INTRODUCING EDSA MEMBERS

 CROATIAN DOWN SYNDROME ASSOCIATION (HRVATSKA
 ZAJEDNICA ZA DOWN SINDROM)


The Croatian Down Syndrome Association (Hrvatska zajednica za Down sindrom, HZDS) was founded 2005 in order to align and integrate the operation of several Down Syndrome organizations in the Republic of Croatia. CDSA represents 8 local Down Syndrome associations in Croatia and around 400 children with Down syndrome and their families.

The constituting members of CDSA are 8 local association: The Down Syndrome Organization - Zagreb, The Down Syndrome Organization 21 - Split, The Down Syndrome Organization of the Međimurje County, The Down Syndrome Organization - Rijeka 21, The Down Syndrome Organization of the Zadar County, The Down Syndrome Organization of the Osijek County, The Down Syndrome Organization of the Dubrovnik - Neretva County, The Down Syndrome Organization of the Virovitica-Podravina County.

Years –range	M or F		Total	%
	M	F		
0-4	49	45	94	6
5-9	134	124	258	16,5
10-14	118	114	232	14,9
15-19	132	103	235	15,1
20-24	96	76	172	11
25-29	63	64	127	8,2
30-34	48	58	106	6,8
35-39	52	55	106	6,8
40-44	42	39	81	5,2
45-49	24	27	51	3,2

50-54	23	28	51	3,2
55-59	15	5	20	1,3
60-64	6	8	14	0,9
65-69	1	4	5	0,3
70-74	1	0	2	0,1
75-79	0	1	1	0,06
85+	1	0	1	0,06
Total	805	751	1556	

In Croatia, a country of 4,2 million inhabitants according to the data from Croatian Institute of Public Health from the end of 2014 in Croatia live around 1600 persons with Down syndrome. Data for the years range 0-4 are not updated as all documents were not arrived in Institute for all babies. From 35-45 babies with Down syndrome are born every year.

Preschool children with DS are mostly included in kindergartens in groups with typical development children partly or full time. Still there are children with DS in groups of children with special needs full time or partly. Unfortunately still some kindergartens hardly accept children with DS. Early intervention is not yet available for all children with DS and also it is not in the range needed for the children with DS. NGOs are trying to close the gap as much as they are possible. CDSA participated in defining of the elementary school pedagogical standard that was accepted by the Croatian Parliament in July 2008, with reference to the introduction of a learning support assistant for children with special needs included in regular educational process. According to the pedagogical standard regular school were open much more for the children with DS. Before that change almost all children went to the special schools and very rare to regular or in the partial integration.

From 2007 Association is involved in integration of nearly each child with Down syndrome in Croatia in regular education process. Around 10% of children with DS is in full integration in the regular educational process with learning support assistant. Another 10% is in partial integration. Others are in special schools or in special programs.

School year	Number of pupils – full integration
2007/2008	7
2008/2009	16
2009/2010	24
2010/2011	30
2011/2012	42
2012/2013	59
2013/2014	68
2014/2015	78

Because of legal situation of persons with disabilities and also persons with DS after 18th birthday most parents keep children/ youngsters into special schools. Since 2010 some parents decided to allow that their children go to the secondary. This year 10 youngsters with DS are in secondary schools and every year will be more as there are more and more children in the regular school in full or partial integration. Also after secondary school will be necessary to find more opportunity and places where persons with DS could work. At the moment just few persons with DS are working on the open market. Others are in institution or at home with their families.

CDSA regularly is giving educations for the parents, learning support assistant, teachers and professionals. There few education ongoing “How to teach children with Down syndrome”, “How to learn mathematics”, “Use of the symbols for teaching children and adults with DS”.

CDSA through the educations “Use of the symbols for teaching children and adults with DS” supports parents and professionals to learn how to work and prepare educational materials for children with DS. CDSA is the owner of more than 60 pieces of software package “Boardmaker with Speaking Dynamically”. Parents can borrow a software package to use as long as they are preparing learning materials for the child. The software package is used for the preparation of materials for encouraging and support speech, learning vocabulary, for working materials in the pre-school years and for the school.

Mathematics is abstract but could be very interesting for children with DS as well. In education “How to learn mathematics” we are giving parents and teachers way of learning with child with DS by using education materials from the market (Numicon, Cuisenaire, Nathan maths material, Vinco maths material) and also prepared education materials by CDSA.

Education “How to teach children with Down syndrome” is for the parents, learning support assistant, teachers and professionals in school when child with DS is going or is in the school. Through this education we are giving information about the ways how children with DS is learning and what it is specific for them, in which area are good and in which they have problems. Also through education we are giving to them view through all eight classes what could be done per each subject. Most professionals doubt that children with DS could stay in regular school when number of the subjects are growing (v.e.g. in Croatia that is fifth and seventh class). Because of that doubt very often we have educations in the school when our child with DS is making that step.

In 2007 CDSA published a handbook entitled „Down syndrome – a guide for parents and experts“. The handbook was prepared by parents of children with DS, special education teacher and speech therapist. The handbook, 2014 fourth edition, is still distributing in

local associations, maternity hospitals, pediatric, GP clinics and welfare centers.

CDSA translated seven publications from Down Syndrome Educational International from UK and six of them are printed already few times. Publications together with handbook „Down syndrome – a guide for parents and experts“ are very used and helpful in every day life of our families with children with DS.

Association collaborated with the Croatian radio and TV in the production of a documentary entitled “The children of love”. Documentary is used as educational video material for parents and professionals.

For any further information please visit CDSA web site www.zajednica-down.hr or <https://www.facebook.com/HRZajednicaDownSindrom>.

The main goals of this Association are the following: to improve the health and social care of people with Down Syndrome, to improve education of children and young adults with Down syndrome, to ensure their proper integration into the society, to provide people with Down syndrome with job opportunities, to initiate and support scientific and other research related to the Down syndrome.

Activities of the Croatian Down Syndrome Association are the following:

- to prompt the introduction of the legislative provisions in the interest of persons with Down syndrome and to act on their behalf;
- to cooperate with organizations that can and will act on behalf of persons with the Down syndrome, their parents or legal guardians;
- to cooperate with authorities, production and service companies and in particular with health care and welfare institutions, the Red Cross and other humanitarian organizations in the Republic of Croatia and abroad;
- to cooperate with any other organizations that take care of the sick or disabled persons in the Republic of Croatia and abroad;
- to cooperate with universities and counseling centers;
- to develop and improve expert competencies regarding Down syndrome;
- to establish and maintain direct contacts with persons with Down syndrome;
- to establish and maintain direct contacts with families of the persons with Down syndrome, people who take care of them, medical experts, etc.
- to provide relevant information to all interested parties via printed and/or audio-visual media, lectures and other media;
- to organize courses, educational and recreational programs for children and adults with Down syndrome.

1. In 2007 The Croatian Down Syndrome Association published a handbook entitled „Down syndrome – a guide for parents and experts“, financed by the Ministry of Science, Education and Sport and the Croatian company Ericsson Nikola Tesla (ETK). The handbook was

prepared by parents of children with DS, physicians, speech teachers, psychologists and social workers. The handbook was promoted in all Croatian cities in which there are active DS organizations, with outstanding results. The Ministry of Science, Education and Sport and the the Ministry of Health and Social Welfare authorized distribution of the handbook in maternity hospitals, pediatric and GP clinics and welfare centers. The first edition was 5500 copies. At the end of 2008 the second, revised edition was published in 3000 copies. (funded by the Ministry of Science, Education and ETK).

2. The Association collaborated with the Croatian radio and TV in the production of a documentary entitled “The children of love”. It is now used as educational video material for parents and experts.

3. The Association is now coordinating translation of the publications by The Down Syndrome Educational Trust – we have planned to translate into Croatian seven publications in the cooperation with the aorganization SOROPTIMIST. Four publications have already been translated and the translations are now being reviewed by experts. The Association is currently lobbying to gain the funds required for printing of these publications.

The Croatian Down Syndrome Association closely collaborates with other organizations of parents of children with special needs (PUŽ & OKO) to overcome problems regarding the inclusion of children and grown ups with special needs into the society. Here we also collaborate with the Ministry of Health and Social Welfare and the Ministry of Science, Education and Sport, the City Office for Education, culture and Sports of the City of Zagreb and the City’s women attorney for children.

The Association’s web page <http://www.zajednica-down.hr/> offers relevant information to all interested parties, in particular about the needs and possibilities of persons with DS, and it facilitates a network of parents and organizations concerned with DS.

The Association repeatedly organizes lectures for parents and experts about functional learning and symbol prompted speech motivation in accordance with the needs of different related organizations, symposiums and conferences.

The Association participated in defining of the elementary school pedagogical standard that was accepted by the Croatian Parliament in July 2008, with reference to the introduction of a teacher assistant for children with special needs included in regular educational process. The Association is envolved in itegration of nearly each child with Down syndrome in Croatia in regular education process.

The Association takes part in organization of an UNICEF Croatia’s project entitled “The first three years are EVEN MORE important”. In 2008 the Association received the funds amounting to EUR 24 000, out of which EUR 8 000 was collected via donations and EUR

16 000 came from the government funds, in particular from the the Ministry of Health and Social Welfare and the Ministry of Science, Education and Sport.



NEWS FROM EDSA MEMBERS



DOWNSIDE UP (Russia)

Charitable fund “Downside Up” informs you about the opening of the multilingual Internet resource on Down syndrome: <http://downsideup.wiki/en/>

This resource aims to provide complete and truthful information about Down syndrome to parents and professionals all over the world. This information includes scientific research in Down syndrome, approaches to working with children, materials about education, social integration, creativity and any other aspects of life of children and adults with Down syndrome.

Downside Up is open to the cooperation with professionals and offers Edsa members to become their partner in the implementation of this Project. Not only organisations can publish the materials on Downside Up Wiki, but also private specialists.

More than 3700 users registered in four months of the Project’s life. Total number of visitors for the last month – 9200.

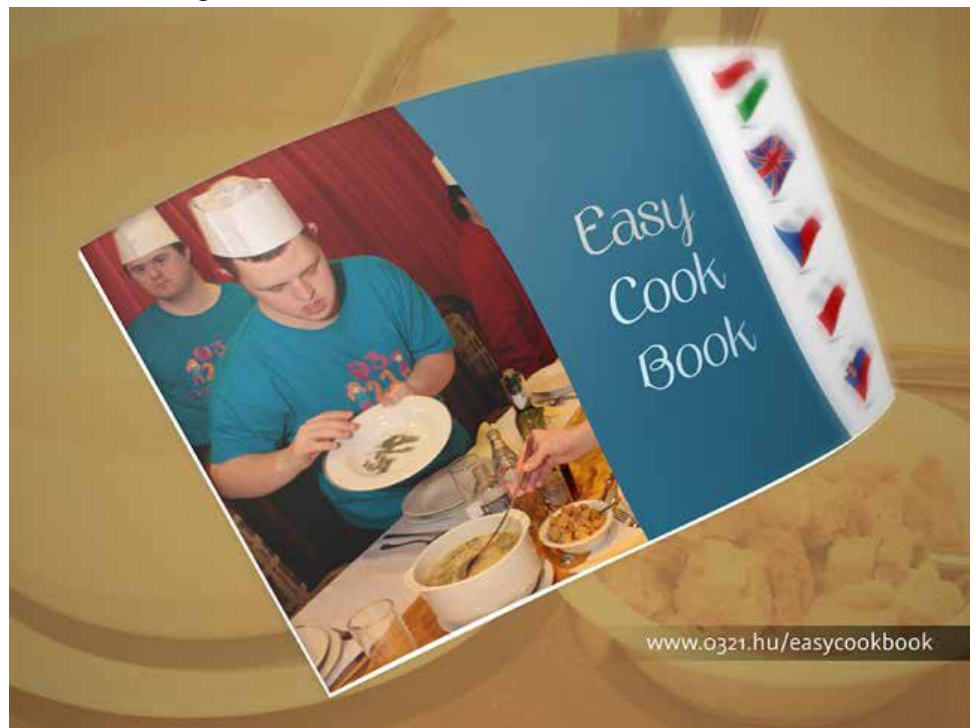
84% of them are from Russia and the rest came from other countries. Information received from Downside Up specialists and partners were published in various formats: images, videos, presentations, articles, magazines and journals, books and archive materials. Send your suggestions and comments to info@downsideup.org

HUNGARIAN DOWN ASSOCIATION (Hungary)

The Easy Cook Book



The Hungarian Down Association proudly presents its first easily accessible, international Easy Cook Book. It introduces you 12 international recipes. Among them you will find your favourite meals, any of which is an excellent choice to invite friends and family for. The Easy Cook Book has been translated into five languages, Hungarian, English, Slovakian, Czech and Polish. The hope is that the Easy Cook Book will reach people with Down syndrome and others with intellectual disability worldwide, so that they can get to know the culinary tradition of different nations. The meals are various. With the Easy Cook Book you can prepare delicious homemade meals: soups, main courses and desserts for those with a sweet tooth. You will love the Easy Cook Book. All 12 recipes are illustrated with photos, they are written in a simple, easy to follow language. The Easy Cook Book drives you to become a great cook now.



Hungarian Down Association would like to thank International Visegrad Fund and all their partners for their active participation. Please click here to read more and to download the cook book <http://0321.hu/easycookbook>

DOWN SYNDROME IRELAND (Ireland)

Nothing tops a pint with dad

This Father's Day, David Clarke pays tribute to his dad Pat, CEO of Down Syndrome Ireland, even though he supports Chelsea.



Like father like son: David Clarke and dad Pat travel the world together giving talks and presentations and attending conferences on Down syndrome. Photo: Steve Humphreys

Most of us feel a twinge of anxiety when we have to make a presentation to strangers, but David Clarke (34) says he's never nervous when he stands up to speak in front of a crowd. David and his dad Pat have travelled the world together giving presentations in Singapore, Cape Town and Vancouver. While in Bali, they gave a joint presentation on participating in elections and the right to vote. "I always vote," says David, who can't wait to visit India in August for the World Down Syndrome Congress. "I voted on the same-sex marriage referendum and was very pleased with the result."

"David has voted in every election since he turned 18, so he told them about his experience," adds Pat, who is CEO of Down Syndrome Ireland. "They wouldn't have reckoned on this in their culture, or expected that a person with Down syndrome could stand up and give a presentation like that." In addition, the charming duo have made presentations at the UN and Council of Europe, and also visited the White House, where they spotted Barack Obama getting into his helicopter.

Pat first met his wife Madeline going to confession, and they were married in 1977 and have four children, Susan, David, Caroline and Emer. They got a shock when David was born with DS, as they didn't know in advance, but were thankful that he didn't have any of the congenital heart problems that affect almost half of babies born with the condition. "We entered into 'coping mode,'" says Pat. "David was great as a baby, and when any difficulties arose, we knew we would

all learn to grow into them. David was always independent. We got him into a mainstream creche, and he never wanted us to bring him in as he wanted to walk in on his own. When it was time to go to school, unfortunately the only place that was available back then was a segregated special school, which meant that David had to travel daily from Trim, where we lived then, to Navan. My work with DSI was only voluntary at that point, but I got involved with setting up the first mainstream education programme for children with DS.” Now living in Drogheda, Pat grew up on a farm in Louth and is the eldest of the late Tom and Tina’s eight children. He went to school at St Patrick’s in Armagh because he thought he might join the priesthood, but that didn’t work out and he trained as an accountant. He was working as a self-employed business consultant prior to becoming CEO of DSI five years ago. He is very excited about the HB Hazelbrook Farm Ice Cream Fundays campaign they’re currently running, where people all around the country are hosting fun ice cream parties and receiving vouchers for free HB Hazelbrook Farm ice cream. The parties provide a vital source of funding for DSI’s essential work, which includes fighting for the implementation of the ‘legal capacity’ legislation, and funding core services in the areas of early development, education, health and independence.

“Dad is good at being the head of DSI and I’m very proud of him,” says David. “He is good to talk to, and I like going out for meals or to the pub for a pint with him - I like a good pint. What drives me mad is that he’s always on the phone.”

David loves soccer and swimming, and represented Ireland at the World Down Syndrome swimming championships, winning a gold medal in Limerick and a silver in Portugal. He also got a red belt in taekwondo, and currently plays tag rugby with a local group. What was he like as a teenager? Did father and son clash when the hormones kicked in? “David was very good and didn’t give us any trouble,” says Pat. “The girls were worse! David was always independent and fairly focused, and he went on to attend Drumcar Park Enterprises, which is a training centre workshop environment.”

David now has two part-time jobs - packing hampers for Gifts.ie, and working with Tesco, Drogheda, where he looks after recycling. He also completed the Latch-On programme, a two-year literacy and technology programme for adults with an intellectual disability. “We noticed the participants’ language skills really improved and David can now do very difficult word searches that he never did before,” says Pat, adding that they are speaking to Trinity College about brain training for people with DS, because they can begin to show signs of dementia and Alzheimer’s from the age of 40, and 60pc will show signs of those diseases by 60.

While he is still living at home, the family is looking to set up support so that David can be in a position to live semi-independently. He wants to learn to cook, and enjoys trying out local dishes while travelling, and even the very spicy foods he encountered in Bali went

down well. "My dad is a good cook, and he can make lasagne," he says. "Mum isn't bad either and she makes spaghetti bolognaise. I make salads as they are a healthy option. I like a fresh fruit salad for dessert and I love cheesecake."

The Clarke men love watching football together, although it can get a bit contentious as David supports Manchester United while Pat's team is Chelsea. We shall say no more about that...

"David is a really fun guy and we have a great time together," says Pat. "I am very proud of his achievements, but a lot of credit has to go to Madeline. While I was out working, she worked extremely hard with David. She made a big effort to get him to socialise, and now we can bring him anywhere and he mixes with everyone. I came in at the nicer parts of it, like getting him to work with me and do presentations, but Madeline has made him into the fantastic man he is today."

Taken from Independent.ie of the 22nd of June 2015

<http://www.independent.ie/life/nothing-tops-a-pint-with-dad-31315243.html>

NEWS FROM THE PROJECTS WITH EDSA MEMBERS INVOLVED IN THE PARTNERSHIP

ON MY OWN... AT WORK (OMO) PROJECT

Lisbon, June 25-26, 2015

The second project meeting was held in Lisbon and was hosted by APPT21.

Cora Halder has attended the meeting on Edsa's behalf.

The Omo project aims to break barriers and open doors for an accessible and inclusive society for people with Down syndrome. The project aims at designing, developing, testing, delivering, as well as diffusing a training method with the goal of enhancing the learning process of people with Down syndrome willing to work in the hospitality business. The project provides the development of advanced educational tools specifically designed for hotel tutors (videos on ways to improve the tutor-trainee with DS relationship) and innovative learning materials (pocket interactive resources) for youngsters with DS who will achieve an internship at a hotel and gain knowledge, skills, and competencies to perform the tasks of selected job positions. For any further information please write to AIPD c/o omoaipd@gmail.com or visit <http://www.on-my-own.eu/>

MAKE THIS NEWSLETTER REALLY YOURS!

Have you got any news that we could publish in EDSA newsletter?
Please send us any information you would like to announce and we shall be happy to disseminate it all over Europe!

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