

ON THE UP

WITH DOWN SYNDROME

WINTER
2003

VOLUME 13

ISSUE 1

SANTA'S ELVES DECLARE 2002 DSAW CHRISTMAS PARTY A HUGE SUCCESS!



Saturday, December 14th, 2002 was busy with the hustle and bustle of the holidays for many of DSAW's member families. A phenomenal time was had by all. Santa was very pleased at the number of good little girls and boys that he was able to see and give some gifts to before his big trip on Christmas Eve.

The Annual Children's Holiday Party was held at the Clarion Hotel and Conference Center across from the airport on Saturday, December 14th. As families arrived, they were greeted by several elves at our registration table and were able to pick up a personalized family ornament for the second year in a row, courtesy of Katy Zanoni. Each child was then given their choice of small toys, courtesy of Playing Mantis. As they proceeded into the ballroom they found tables arranged with beautiful centerpieces, crayons and coloring sheets for all to enjoy!

A bountiful buffet table was also being prepared for a delicious

lunch, which would not have been possible without the unending efforts of Nicole and Loren Lembke and their coordination of US Foodservice. We would like to take this opportunity to offer a special thank you to Brigitte Wagner and Brad Menzel, food coordinators for US Foodservice and a very special thank you to Elliot Adkins, President of US Foodservice. They have graciously lent a helping hand to several of DSAW's events over this past year and without their support, the lunch buffet that was served would not have been possible. A special thank you also goes out to Ellen Mayer and Pam Albrecht, our sandwich servers. Thank you both for making sure the buffet was always plentiful and the food lines moved smoothly!

Shortly thereafter, Santa arrived and made his way through the crowd over to his throne. More of Santa's elves were waiting to help him hand out presents to approximately 115 children. Santa's helpers at Bank One, Hasbro and KB Toys were hard at work earlier in the year to make sure that each child went home happy that day. An extremely warm and heartfelt



thank you goes out to Pam Albrecht, the Volunteer Coordinator of Bank One and all of her little helpers at Bank One as well as to John Michlig, who were able to add a little sparkle to each child's eye as they jumped off Santa's lap and opened their presents. As each child received their gift, they also were able to have their picture taken with Santa and take it home in a beautiful,

personalized holiday picture frame serving as a small memento for the day. A special thank you goes out to Lakeshore Photography for providing a backdrop for us to use. Lakeshore Photography of South Milwaukee has a great deal of experience working with people with special needs. They have told DSAW they would be happy to entertain any questions or comments from anyone, (414) 762-1358. Thank you to our freelance photographer, Andria



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TO OUR NEW MEMBERS:

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Greg, Mary Ann,
Grace & Gabrielle Proffitt
Lynn & Matthew Raetz
Diane & David Sebek

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A VALENTINES DAY POEM OF LOVE

THE GIFT OF YOU

By Allison Chambers Coxsey

A gift was given to me,
A rare and wondrous thing,
Filled with love, this cherished gift,
Was like the kiss of Spring.

A gift that changed my path in life,
From places I had been,
The treasure that you freely shared,
Brought peace and joy within.

The gift was sweet and simple....
As love should always be;
My life is blessed forever,
That gift you gave to me.

COMMITTEE VOLUNTEERS, ANYONE??

As those who enjoyed the DSAW Holiday Party can attest to, the events that DSAW sponsors are getting bigger and BETTER every year. As is with all good things, it takes a lot of time and talent to make these events a success. Annual event Coordinators have begun planning for the 2003 events and need your input.

Please look over the event listings and volunteer your time and talent to make the sponsored events a great success!!

Conference Taskforce (ongoing)
DSAW News and Newsletter
(ongoing, publishes 5 bi-monthly newsletters)
Annual Picnic (to be held in summer)
Tom Pipines Golf Outing (scheduled for August 18, 2003)
Buddy Walk (annual event held in October)
Holiday Party (annually held in December)

Bring your friends and make new ones by joining a committee and help make 2003 the best year DSAW has ever had. Please contact Ellen at the DSAW Office at the numbers located on the back of this newsletter and join us!

Continued from Page 1

Humphreys-Ward for donating her time, creativity and patience that day. The pictures proved to be a superb touch to an extraordinary day.



As families picked up their toys and pictures, they were able to go to the New Berlin Therapy Activity Area. Thank you very much to Dana Parisi and her crew for setting up such a wonderful and creative play area for all to enjoy. All of the children loved the ball pit, the mini roller coaster and the multitude of other activities. The parents really appreciated it, too! We would also like to extend a special thank you to our DJ, Mr. Ed Dunn of Music Worth Hearing, who provided festive holiday music to enjoy throughout the party. Right before the end of the party, new Board President, Gary Zaroni, stepped up to the microphone to announce our raffle prize winners. All of the centerpieces, which included festively decorated candles and brightly colored Poinsettia plants, were donated by the Loyo, Albrecht and Mayer families and were raffled off as door prizes. No one went home empty handed!

Beth Steimke and her staff at The Clarion Hotel and Conference Center provided an exquisite atmosphere and an incredible location for DSAW to host our annual children's party. We would like to say Thank You to The Clarion Hotel and Conference Center, Beth and the hotel staff for the donation of the room and for everyone's gracious manner. Without your generosity we would not have been able to provide such an awesome party in 2002!

And last, but certainly not least, The Holiday Party Committee would like to say thank you to all the wonderful volunteers that came in that day and helped to set up tables with the crayons, coloring sheets and centerpieces, chaperone the activity area, help Santa organize and hand out gifts, assist the photographer, registration and the various other responsibilities that were asked of you. You all did a fantastic job and without you we would not be able to hold such successful events year after year.

Thank you and DSAW wishes everyone a healthy and prosperous 2003!



DSAW BRAG BOOK



Dylan Kligora

Hannah Platkowski

**Send your pictures, digital or otherwise,
to the DSAW office and let us
show off your special someone!!**

LOOKING FOR HELP WITH YOUR CHILD'S IEP?

ATTEND THIS FREE SEMINAR!!

"How To Get an Effective IEP and Make Sure It's Being Followed", is a seminar for parents of children with disabilities sponsored by a grant from the Altrusa Club of Appleton, WI. Learn what to do **before** the IEP meeting to get prepared for the meeting, **during** the IEP meeting to be an equal partner with the school staff and **after** the IEP meeting to make sure your child's IEP is being followed. Find out about positive strategies to utilize if the IEP is not working for your child as well as if the IEP is not being implemented. This seminar will be held on March 10, 2003 at 6:30 p.m. at the Thompson Center in Appleton, WI.

Register for this seminar and request your information packet by e-mail by contacting corinneq@athenet.net. Parents should bring their child's current IEP.

CHECK OUT OUR NEW LOOK ON THE WEB

The Down Syndrome Association has a new webpage with more information than ever before. Check us out on the web at www.dsaw.org. A more up-to-date calendar and a downloadable OnTheUp Newsletter area are just two of the recent additions. Give the site a preview and then e-mail the office with your comments or suggestions for additions.

WHY A CLINIC FOR PEOPLE WITH DOWN SYNDROME?

Terri Couwenhoven MS, Clinic Coordinator

I must admit I asked myself this question when I first applied for the Project Manager position of the newly funded Down syndrome Clinic of Wisconsin back in 1995. At that time my daughter Anna was six years old and I was still attempting to suppress early health care experiences we had had as parents of a newborn with Down syndrome. I wanted to forget the way the doctor who delivered Anna used the word *Mongoloid* instead of Down syndrome when he initially shared information about her diagnosis. And two weeks later when I called to speak with my physician because Anna's coloring seemed more "bluish", I wanted to forget the response from the doctor-on-call. He said (I quote),"don't be offended if I ask you this question but is this your first child?" It was, but it didn't matter. Later that night, we ended up in the ER, rode in an ambulance to CHW and learned she had a major heart defect that had gone undetected.

Why a clinic for people with Down syndrome? Because the above scenarios don't need to happen, but still do. Because there are still many physicians and health care providers who see few patients with Down syndrome and need information about how to provide quality care. Because families need a place they can go to or call when they need interpretations, explanations, recommendations or questions answered. Because increasingly, as Down syndrome clinics emerge around the country (there are approximately 20 specialty clinics for people with Down syndrome in the US) and world, improved qualitative and quantitative information about health and medical issues is emerging. Families and physicians in the area need to know where they can go to find information when it becomes available. We need to have a clinic because there is still so much we don't know. Collaborative, multi-site research studies are just now becoming more doable.

All of the above reasons are what prompted Dr. David Smith, Medical Director of the Down Syndrome Clinic of Wisconsin, and Mickey Harris PhD from the Medical College of Wisconsin to seek funding to start a Down Syndrome Clinic in Wisconsin back in 1995. They wanted the clinic to work towards improving the health and well being of people with Down syndrome and believed this could be achieved best through patient care, physician and health professions training, programming for families, and research. We saw our first patient at the clinic on November 4th, 1996 and since then have seen 300 more. For those of you who aren't aware of the clinic here's some general information:

CLINIC LOCATION

The Down Syndrome Clinic of Wisconsin is now located on the second floor of Children's Hospital of Wisconsin in Clinic E (we share space with the Rheumatology clinic). Clinics are generally scheduled the first Wednesday of the month.

WHO TYPICALLY COMES TO THE CLINIC AND WHY DO THEY COME?

Both children (58%) and adults (41%) with Down syndrome are seen at the clinic. Although there may be many reasons a family comes to see us, most often they come because they have a specific question or concern (and often multiple concerns) regarding their loved ones health. Other families are not as concerned about specific "problems", but come to the clinic as a way to make sure

they're on track with health maintenance or to have their family member examined for the first time by someone who has some expertise in caring for people with Down syndrome.

WHAT HAPPENS DURING A CLINIC VISIT?

All new patients visiting the clinic receive a full physical examination and hearing test (if not done during the past year). Lab work, x-rays, and other routine screenings (thyroid, celiac disease, etc.) that are recommended for people with Down syndrome can also be done if needed. The remainder of the clinic visit can look different depending on the needs of the family. During the initial phone call, I assess the needs of the family and then make recommendations to help shape the visit to meet family needs. For example, a young adult with weight issues can schedule time with a nutritionist during their visit to the clinic. A family whose child may have complicated feeding issues may spend the morning in Feeding Clinic before meeting with Dr. Smith in the afternoon. A genetic consultation might be a part of a visit for a family that received no counseling services after their newborn was delivered. Other evaluations such as Speech, OT, or PT, are commonly coordinated with a visit to the Down syndrome clinic. Additional evaluations are often ordered as a recommendation for future care following the visit to out clinic as well.

AFTER THE CLINIC VISIT

Following the visit to the clinic, a comprehensive report is mailed to the family and primary care physician that includes recommendations for future care. HealthCare Flow Sheets, designed to be placed directly into the patient, make monitoring for preventative health care easier for the physician. These guidelines can also be accessed on our web page (www.chw.org - go to Down Syndrome Clinic). Results of screenings and tests performed during the visit are also included. Dr. Smith is also available for consultations should your primary care provider have future health care questions.

HOW DO I SCHEDULE A VISIT?

To schedule a visit at the clinic call me at 414-266-6259 or e-mail me at tcouwenhoven@chw.org or dscw@chw.org.

OTHER STATE DS RESOURCES

Waisman Center (www.waisman.wisc.edu) – This center, located in Madison, was created to advance knowledge about human development, developmental disabilities (including Down syndrome) and neurodegenerative diseases. The center accomplishes its mission by conducting research, and providing training, services, and community outreach. They are presently conducting cognitive and communication research with adolescents who have Down syndrome. For more information contact Melissa Murphy 608-263-5145 or refer to our web page www.chw.org for more detailed information.

Ms. Couwenhoven will be our guest speaker at the next DSAW membership meeting held on February 13, 2003 at 6:30 p.m. at the DSAW office. Plan to attend and find out more information about the Down Syndrome Clinic of Wisconsin.

PLANNING FOR OUR LOVED ONES FUTURE A RECAP OF THE NOVEMBER MEMBERSHIP MEETING

Guest speaker at the last DSAW membership meeting was Carrie Klump of the ARC. Carrie provided our members with a wonderful presentation on planning for the future of a loved one with a developmental disability. Carrie and the 14 DSAW members who attended were able to discuss their real life experiences on the topic as well as focus on the pros and cons of legal guardianship for their child(ren).

Carrie discussed the "Letter of Intent" as an important document that would be very beneficial for the caregiver of the

person with special needs. This document essentially describes the lifestyle and special needs of the person to assist the caregiver in understanding and providing that specific care. She also discussed a new program, The Joseph P. Kennedy, Jr. Foundation Project. The purpose of this project is to create new legal options to increase quality, affordable housing for people with developmental disabilities. The project will allow families to leave their homes for the benefit of their adult relatives with developmental disabilities. The creation of these new legal options

will make it possible for adults with developmental disabilities to have permanent, affordable homes in familiar communities.

The DSAW office has copies of the handouts that were distributed at the membership meeting. Please contact Ellen at the DSAW office with your request. For additional information on the Kennedy Project, you may also contact Lisa Mills, Project Coordinator, at 1-888-894-9646 or e-mail at Lmills@execpc.com.

BOOK REVIEWS

Incredible Edible Gluten-Free Food for Kids: 150 family-tested recipes

By Sheri L. Sanderson

This new release from Woodbine House is a cookbook of gluten-free recipes that appeal to children and are easy-to-make (appealing to parents!). Recipes are included for snacks; breads; breakfast/lunch and dinner ideas; salads and vegetables; soups and stews; and sweet treats. There's also an overview of celiac disease, advice about managing meals outside the home and tips for coping with food allergies. I know what gluten-free diets are, but my daughter does not have celiac disease and we don't follow "the diet". So, I asked a parent of a child with Down syndrome and autism who follows a dairy, soy and gluten-free diet to check out the book and share her thoughts. She said the book is thorough and packed with information for those just starting on "the diet", which is often an overwhelming and stressful time. She was rather surprised that many of the recipes contain dairy products, because many children on a gluten-free diet also avoid dairy. However, all in all, she sees it as "an excellent book for those who're just starting out on this gluten-free journey."

The Down Syndrome Nutrition Handbook: A Guide to Promoting Healthy Lifestyles

by Joan E. Guthrie Medlen R.D, L.D Published by Woodbine House, 2002. ISBN: 1-890627-23-2

Reviewed by Terri Couwenhoven

I have known this book was in the works for some time now so was quite excited when one arrived at the clinic. Joan, author of the book, is also editor and often a contributing writer for *Disability Solutions*. After years of copying segments of her publications for patients and their families, I was grateful to have one book with most everything I would need in the area of nutrition and exercise in one spot!

This book is comprehensive and will grow right along with your child. From breast and bottle feeding for infants to teaching your teen or adult to cook and plan menus, the book is filled with practical teaching ideas that will help us help our children work towards healthier lifestyles. The book includes sections on Building Healthy Attitudes, Nutrition-Related Concerns for People with Down syndrome (celiac disease, diabetes, and alternative therapies), Teaching Healthy Choices and Encouraging Healthy Lifestyles, and Sample Learning Activities. My favorite chapters included Food and School (a biggie for many families), Weight Management and Fitness, and Cooking Corner. A great reference book for the family bookshelf! The book can be purchased online at www.woodbinehouse.com or ordered through any bookstore.

DETERMINED TEEN OVERCOMES OBSTACLES TO CREATE A LIFE SHE LOVES

*By Cooper Munroe
Pittsburgh Post Gazette*

By all accounts, Katherine Iris Apostolides of Fox Chapel, is a remarkable young woman. Katie Apostolides has been honored for the volunteer work she does at Children's Institute of Squirrel Hill. Apostolides, 19, was once a patient there because she has Down syndrome. Now, she helps children who have a variety of disabilities.

The Fox Chapel Area High School senior, known as Katie, maintains straight As on her report card, has been on the high school cheerleading team for the last four years, has been honored for her volunteer work, has ice skated competitively and has written for the school newspaper. In addition, she speaks publicly to local groups, plays piano and models clothes in advertisements for regional department stores.

Her accomplishments are particularly notable because when Apostolides was born 19 years ago, she was diagnosed with Down syndrome. It hasn't held her back.

Apostolides, who loves reading mystery novels and fashion magazines and going to the movies with friends, describes herself as a normal teenager. "And I am doing great at it," she added. It is amazing, a dream come true," said her mother, Paulette Apostolides. "When Katie was a little girl, we prayed and prayed she would be able to live a life with dignity, relative independence and would find joy in helping others. And now, just look at her."

Paulette Apostolides said her daughter's determination is the main reason she has accomplished so much "Katie cheer led us from the beginning. She worked so hard to achieve things. She was the one who did it." It has been a long hard journey.

Dr. Heidi Feldman, a professor of pediatrics at Children's Hospital and the University of Pittsburgh, first met Katie when she was working at the Down Syndrome Center at Children's Hospital in the late 1980's. She found her to be a "lively and wonderful person." In March 2001, Feldman was named the first person to hold the newly created Ronald L. and Patricia M. Violi Endowed Chair in Child Development. The chair was established to honor the CEO of Children's Hospital, Ronald Violi, with a focus on Down syndrome-related health care. A black tie gala was held in downtown Pittsburgh to celebrate the Violi Chair and Feldman was asked to speak about advances in treatment of Down syndrome.

Feldman thought the best way to illustrate her speech was through example. She asked Katie Apostolides to come to the event and share a few words about growing up with Down syndrome. "Katie, who was 17 at the time, came up to the podium with so much confidence and she was dressed in the most gorgeous powder blue gown. I would have loved to have had that dress," Feldman said. Without notes, Apostolides spoke about her experiences for a few minutes and then, according to Feldman, said she wanted to add one more thing.

"My parents don't know I am going to say this," she told the group of Children's Hospital executives, trustees and physicians. Grabbing both sides of the lectern, Apostolides said loudly and slowly: "I love my life."

"There wasn't a dry eye in the house," Feldman said. And then, Katie Apostolides got a standing ovation.

For the complete story, please visit: www.postgazette.com/neighborhood/20021224ncoverp2.asp.

ADULT TRAVEL OPPORTUNITIES

Wisconsin Easter Seals is proud to announce a new service for adults with physical and cognitive disabilities. W.E.S.T. Adventures offers a variety of trips for those who have a spirit of adventure and a need for personal assistance. Wisconsin Easter Seals Travel (W.E.S.T.) Adventures is not just a travel agent for people with disabilities. They are a full service tour operator that specializes in premium service with exceptional staff.

W.E.S.T. Adventure trips are small, intimate groups – usually eight to twelve guests. Trips are designed for adults over the age of eighteen who have a disability as well as enjoy socializing with the company of other guests. Individuals who use wheelchairs or other assistive devices are welcome on the trips. Also welcome are guests who need assistance with eating and other activities of daily living.

W.E.S.T. Adventure trips are lead by a group of highly trained guides who have experience working with adults with disabilities. Depending on the needs of the guests and the nature of the trip, there is always at least one guide for every two guests. A typical trip would include eight guests and five guides. Each trip includes leaders who are first aid, CPR and medication administration certified. A certified lifeguard is always available when a trip includes swimming or other water activities.

An example of a recent adventure taken the first week of January was a 5 day/4 night trip to Chicago. This all-inclusive adventure cost \$895 per person. All transportation, accommodations, recreation and dining was included in the price. This Spring W.E.S.T. Adventures is planning a trip to Branson, MO with a late summer trip to the Twin Cities. For more information, please contact Stuart Mace at (608) 277-8288 ext. 126.



JOIN FRIENDS AND FAMILIES OF THE DOWN SYNDROME ASSOCIATION OF WISCONSIN AT THE OUTBACK!

Outback Steakhouse has teamed up with DSAW to sponsor an Aussie fundraiser. Outback Steakhouse in Greenfield, WI will open its doors to DSAW families and friends only from 11:30 to 2:00 p.m. on April 6th, 2003. So no worries, mate, for \$10/per person enjoy your choice of sirloin steak or 8 oz. grilled chicken breast, salad, bread, soda, tea and coffee. Regularly, this meal would cost a bloke \$20 but on April 6th, it's only half price! All food proceeds, yes-every one of those ten dollars, goes directly to the Down Syndrome Association of Wisconsin.

Milk, juice and alcoholic beverages will be available at an extra charge. So, no worries!

Reserve seating is required and will be limited to 150 people on a first come, first serve basis. Reserve your spot today by filling out the form below and returning it, with your payment, to the DSAW office.

Reservation deadline is March 15th, 2003. Questions?? Call Ellen at (414) 327-3729

Please indicate names of attendees check one entrée request per attendee and total the amount of payment on the form below. Mail this form and your check, made payable to DSAW, to:

Down Syndrome Association of Wisconsin
9401 W. Beloit Rd., Suite 112
Milwaukee, WI 53227

Name of Attendee _____	<input type="checkbox"/> Sirloin Steak	<input type="checkbox"/> Chicken Breast
Name of Attendee _____	<input type="checkbox"/> Sirloin Steak	<input type="checkbox"/> Chicken Breast
Name of Attendee _____	<input type="checkbox"/> Sirloin Steak	<input type="checkbox"/> Chicken Breast
Name of Attendee _____	<input type="checkbox"/> Sirloin Steak	<input type="checkbox"/> Chicken Breast
Name of Attendee _____	<input type="checkbox"/> Sirloin Steak	<input type="checkbox"/> Chicken Breast
Name of Attendee _____	<input type="checkbox"/> Sirloin Steak	<input type="checkbox"/> Chicken Breast

Total Submitted \$ _____

Please list a contact name and phone number should there be questions with your reservation:

Name & Phone: _____

INTERESTING WEB SITES

WWW.ENC.ORG

Eisenhower National Clearinghouse: ENC's mission is to identify effective curriculum resources, create high-quality professional development materials, and disseminate useful information and products to improve K-12 mathematics and science teaching and learning. ENC acquires and catalogs mathematics and science curriculum resources, creating the most comprehensive collection in the nation. They also serve all K-12 educators, parents, and students with free products and services.

Editors Note: I checked this site out for Alec during his science unit on the human body and found it very helpful.

WWW.LEARNINGPAGE.COM

Sister site of www.sitesforteachers.com has downloadable, free thematic worksheets for use with your child. The worksheets are clear, uncluttered and easy to follow. In addition, they have printable books under categories such as vocabulary builders, scholastic themes and more. You must be a member to access their services but membership is FREE.

Editors Note: Check this one out!



Membership Application

New Member Renewal Gift Membership

Name _____

Address _____

City _____

State _____ Zip _____

Phone _____

E-Mail Address _____

Parent Grandparent Aunt / Uncle Sibling Other

If this is a gift membership, list recipient's information above and write your name here: _____

MEMBERSHIP LEVEL

\$15 one year \$25 two years

Additional Donation enclosed: \$ _____

Please enclose any names and addresses of others who may be interested in helping DSAW achieve its goals.

Mail this application with your check to:

DSAW • 9401 West Beloit Road, Suite 112, Milwaukee, WI 53227

ON THE UP WITH DOWN SYNDROME

Newsletter is published quarterly by the Down Syndrome Association of Wisconsin.

DSAW's **mission** is to provide support to families and individuals with Down syndrome through education, information, and the exchange of ideas and experiences.

The **vision** of the Down Syndrome Association of Wisconsin is the understanding of the value of people with Down syndrome in our lives and the community. We will continue to strive towards full acceptance, full access, full life and full potential.

The **policy** of the Down Syndrome Association of Wisconsin is not to endorse any medical, therapeutic or special education alternatives. The Down Syndrome Association of Wisconsin is a volunteer group consisting of people who wish to create an optimistic outlook about Down syndrome for our families and others. The purpose of this newsletter is to provide a source of information to the community and members on issues related to Down syndrome.

DSAW Office is located at
9401 West Beloit Road, Suite 112,
Milwaukee, WI 53227
Phone: (414) 327-3729 or (866) 327-DSAW
Fax: (414) 327-1329
E-Mail: dsaw@globaldialog.com
Web Site: www.dsaw.org

Thanks to **Index Printing** for their hard work that goes into the production of the newsletter.



9401 West Beloit Road, Suite 112, Milwaukee, WI 53227

DSAW IS A NON-PROFIT ORGANIZATION

PLEASE CHECK YOUR MAILING LABEL.
IF THERE IS A NUMBER AT THE END OF YOUR NAME, THAT IS
YOUR MEMBERSHIP EXPIRATION DATE.

**IF THERE IS NO NUMBER,
YOUR MEMBERSHIP HAS EXPIRED . . .
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**IF YOU HAVE NOT YET JOINED DSAW,
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