

# SibShops Overview

Sibling Support Project

Sponsored by UF College of Medicine, Jacksonville

Autism Center

CARD



# What Are SibShops?

## ► TAKE AWAY:

1. Families will obtain an understanding of what SibShops have to offer for the family member who will have the longest-lasting relationship with a person who has a disability
2. Families will find out how to register for upcoming SibShops in St Johns County.

# What Are SibShops?

- ▶ For the adults and agencies that sponsor SibShops
- ▶ SibShops are evidence of their loving concern for the family member who will have the longest-lasting relationship with a person who has a disability.



# Why Sponsor SibShop?

- More than 6,000,000 siblings of children with disabilities in the U.S.
- Siblings frequently have the worst deal
  - Asked to be too independent too soon
  - Asked to be a primary caretaker
  - Miss out on childhood experiences (Scouts, sports, sleepovers)
  - Expected to be the lifelong caregiver



# Why Sponsor SibShop?

- ▶ The patient is never the child with the disability-

it is the entire family



# Why Sponsor SibShop?

- ▶ Look for the “15 minute” date.
- ▶ Unscheduled- not really



# What Are SibShops?

- For the adults and agencies that sponsor SibShops
  - Opportunities for brothers and sisters of children with special needs to obtain peer support and education within a recreational context
  - Reflect an agency's commitment to the family members in developing long-lasting relationships with the person with special needs





# What Are SibShops?

- ▶ They're peer support and education programs
- ▶ For school-age brothers and sisters.
- ▶ A forum where they can talk about their lives



# What Are SibShops?

- ▶ For the kids who attend them, SibShops are pedal-to-the-metal events where they will meet other sibs (usually for the first time)
  - ▶ have fun, laugh, talk about the good and not-so-good parts of having a sib with special needs
  - ▶ play some great games,
  - ▶ learn something about the services their brothers and sister receive, **and**
  - ▶ have some more fun.



# What Are SibShops?

- ▶ For the young people who attend them, they are events, which are
  - ▶ Lively
  - ▶ Energetic
  - ▶ Loving

# Are SibShops A Form of Therapy?

- SibShops are events!
  - Not therapy
  - Effects may be therapeutic (bonus)
- The SibShop model takes a wellness perspective.
  - They're a celebration of the many lifelong contributions made by brothers and sisters of people with special health and developmental needs.

# What Are SibShops?

- ▶ An NPR piece with Neal Conan and *Talk of the Nation* from September 2012 on SibShop, with Don Meyer, the SibShops developer.
- ▶ <http://www.npr.org/2012/09/25/161754564/siblings-with-special-needs-change-childhood>

# Are SibShops A Form of Therapy?

- SibShops
  - Reflect a belief that brothers and sisters have much to offer
  - Intersperse information and discussion activities with
    - Games
    - Crafts
    - Unique activities
  - Provide opportunities for peer support
  - Include guest speakers from time-to-time



# Are SibShops A Form of Therapy?

- ▶ Trained Facilitator always keeps an eye open for children who need further assistance
- ▶ Refer children to additional resources in the community

# Who Attends SibShops?

- ▶ Siblings!
  - ▶ Most siblings are siblings of children with developmental disabilities
  - ▶ Come from diverse backgrounds
- ▶ Originally developed for siblings 8 – 13 yrs.
- ▶ Adapted to include:
  - ▶ Slightly younger children and slightly older teens
  - ▶ Children with other medical conditions (e.g. cancer, other health impairments, and mental health)
  - ▶ Children with parents who have special health conditions





# Who Sponsors SibShops?

- School districts
- Agencies (e.g. UF Jacksonville Autism Center, Easter Seals, developmental disabilities councils, chapters of the Arc, Autism Society)
- Children's hospitals
- Intervention centers
- Park and recreation programs
- Churches
- Any collaborative organization

# Who Facilitates and Who Assists?

- ▶ Run by a team
  - ▶ Service providers
    - ▶ CARD Clinician
    - ▶ Teacher/special education teacher
    - ▶ Social worker
    - ▶ Speech and Language or Occupational Therapists
    - ▶ Nurse, etc.
  - ▶ Family members



# Who Facilitates and Who Assists?

- Suggested:
  - Service providers lead meetings
    - Knowledge about special needs populations
    - Know resources in the community
  - Parents support the efforts



# Parents

- Parents are often the driving force in getting a SibShop started, but they are not usually the best people to run the SibShops their own children attend.
- There is plenty of behind-the-scenes work for parents to do to support a SibShop effort.



# Facilitators

- The facilitator who is a service provider will know about the special needs represented in the group and about services available in the community.
- We very much like having adult sibs as SibShop facilitators--and adult sibs tell us that they get much out of running the program.



# Facilitators

- Regardless of whether the facilitator is a family member or service provider, we seek certain qualities in a good SibShop facilitator.
- We want them to truly enjoy the company of kids
- Have had experience working with kids
- Be especially good listeners
- Have the ability to convey a sense of joy, wonder, and fun.



# Qualities of A SibShop Facilitator

- ▶ Must be trained\*\*\*
  - ▶ SibShops training
- ▶ Must have experience working with children
- ▶ Enjoy the company of children
- ▶ Be able to play games, sing songs, express joy, and be curious,
- ▶ Be a good listener
- ▶ Have a sense of humor
- ▶ Be respectful of all participants





# What Is The Optimal Number for A SibShop?

- Ideally, 12 - 20 children
- Less than 12 children?
  - Can have 5 children and still be successful!

# When Are SibShops Offered?

- After school
- Early release day
- Teacher planning/work days
- Saturday's
  - Time:
    - Want to have ample time for: information sharing activities, discussions, games, songs, crafts, and food/snacks

# What Are the Goals of the SibShop Model?

- Provide siblings of children with special needs opportunities
  - To meet other siblings in a relaxed, recreational setting
    - Reducing the feeling of isolation
    - Promoting informal sharing and friendships
  - To discuss common feelings, concerns, and joys
  - To learn from each other and how to handle situations commonly experienced/shared by siblings of children with special needs
  - To learn more about their siblings disability and how it impacts their lives
  - To share what's learned with others



# What Are the Goals of the SibShop Model?

- Provides parents and other professionals an opportunity to learn more about the concerns, views, and visions frequently experienced by siblings of children with special needs



# Are There Any Guarantees?

- ▶ Parent Assurance
  - ▶ When a parent sends their child(ren) to a SibShop, they are sending them to a program that is true to the spirit and goals of the SibShop model
- ▶ Child Assurance
  - ▶ Good time
- ▶ SibShop Trademark
  - ▶ The program must be registered in order for a SibShop to call itself a “SibShop”

# How Often Are SibShops Held?

- Frequency depends on needs and resources!
- SibShops can operate as a club
  - Weekly
  - Bimonthly
- SibShops can operate as a class
  - Example: 5 SibShops, meeting once a month, registration.
    - Encourages same participants

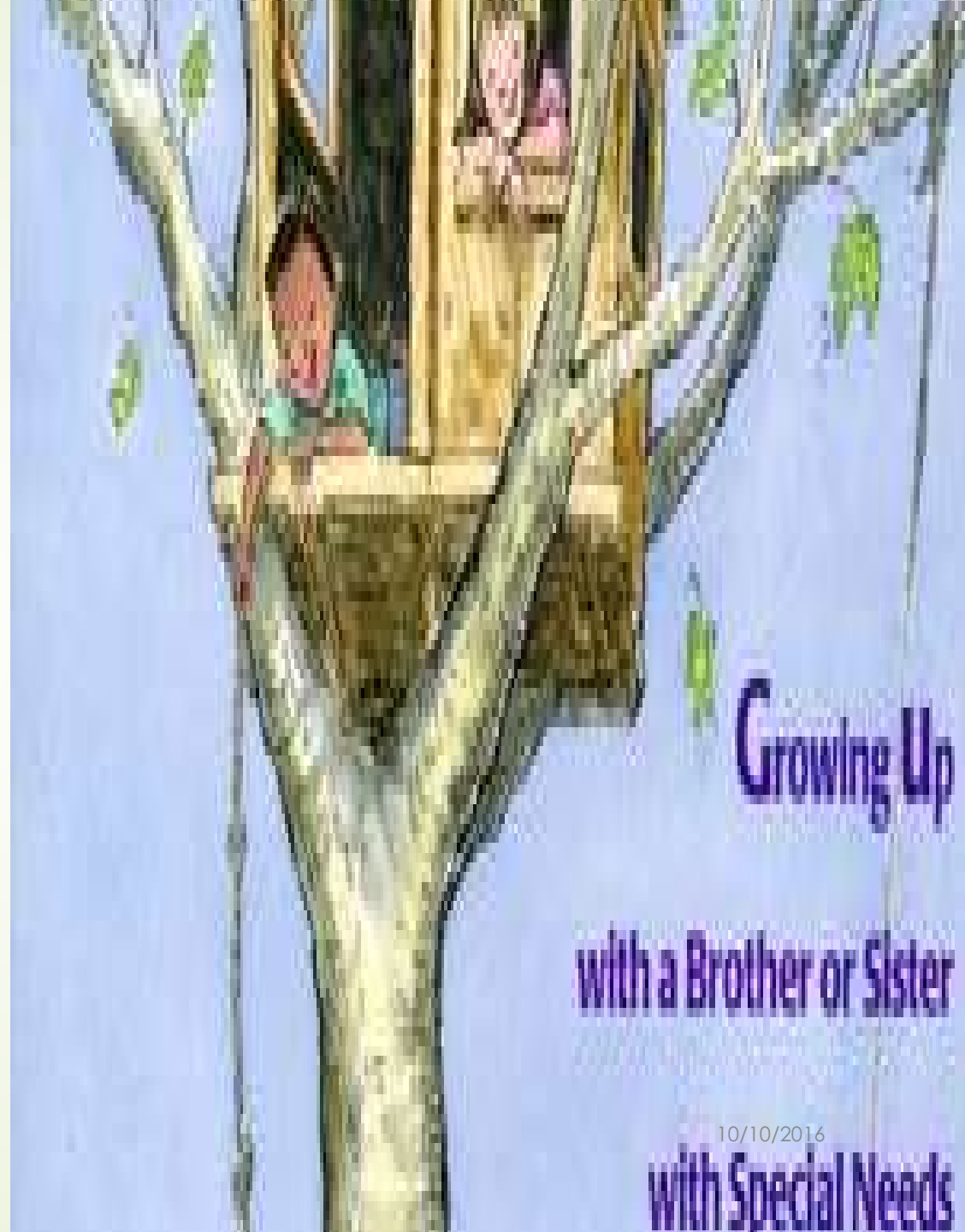


# Resources

- Sibling Support Project Website.
- <https://siblingsupport.org/SibShops>

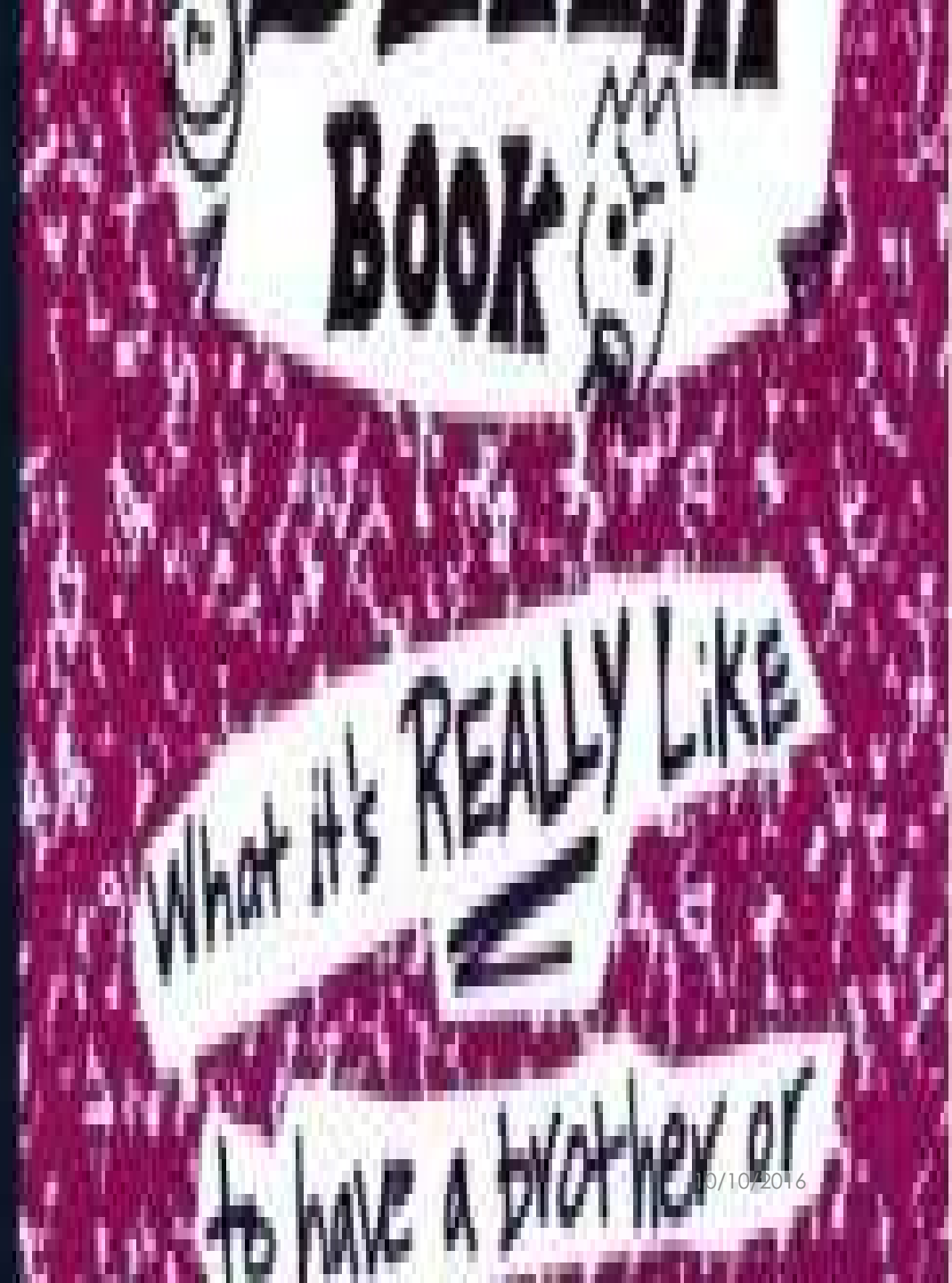


- "I can't imagine having a plain old sister," writes ten-year-old Ryan Clearwater.
- He is one of 45 siblings in **Views from Our Shoes** who share their experience as the brother or sister of someone with a disability.
- The kids whose essays are featured range in age from four to eighteen and are the siblings of youngsters with a variety of special needs including autism, cerebral palsy, developmental delays, chronic health conditions, attention deficit disorder, hydrocephalus, visual and hearing impairments, Down syndrome, Prader-Willi and Tourette's syndrome.
- Their personal tales introduce young siblings to others like them, perhaps for the first time, and allow them to compare experiences.
- A glossary of disabilities provides easy-to-understand definitions of many of the conditions covered.



- Give teenagers a chance to say what's on their minds, and you might be surprised by what you hear from a group of 80 teenagers, from all over the United States and abroad, to talk about what it's like to have a brother or sister with special needs.
- Their unedited words are found in **The Sibling Slam Book**, an honest, non-PC look at the lives, experiences, and opinions of siblings without disabilities.
- Formatted like the slam books passed around in many junior high and high schools, this one poses a series of 50 personal questions along the lines of:
  - “What should we know about you?”
  - “What do you tell your friends about your sib's disability?”
  - “What's the weirdest question you have ever been asked about your sib?”
  - “If you could change one thing about your sib (or your sib's disability) what would it be?”
  - “What annoys you most about how people treat your sib?”

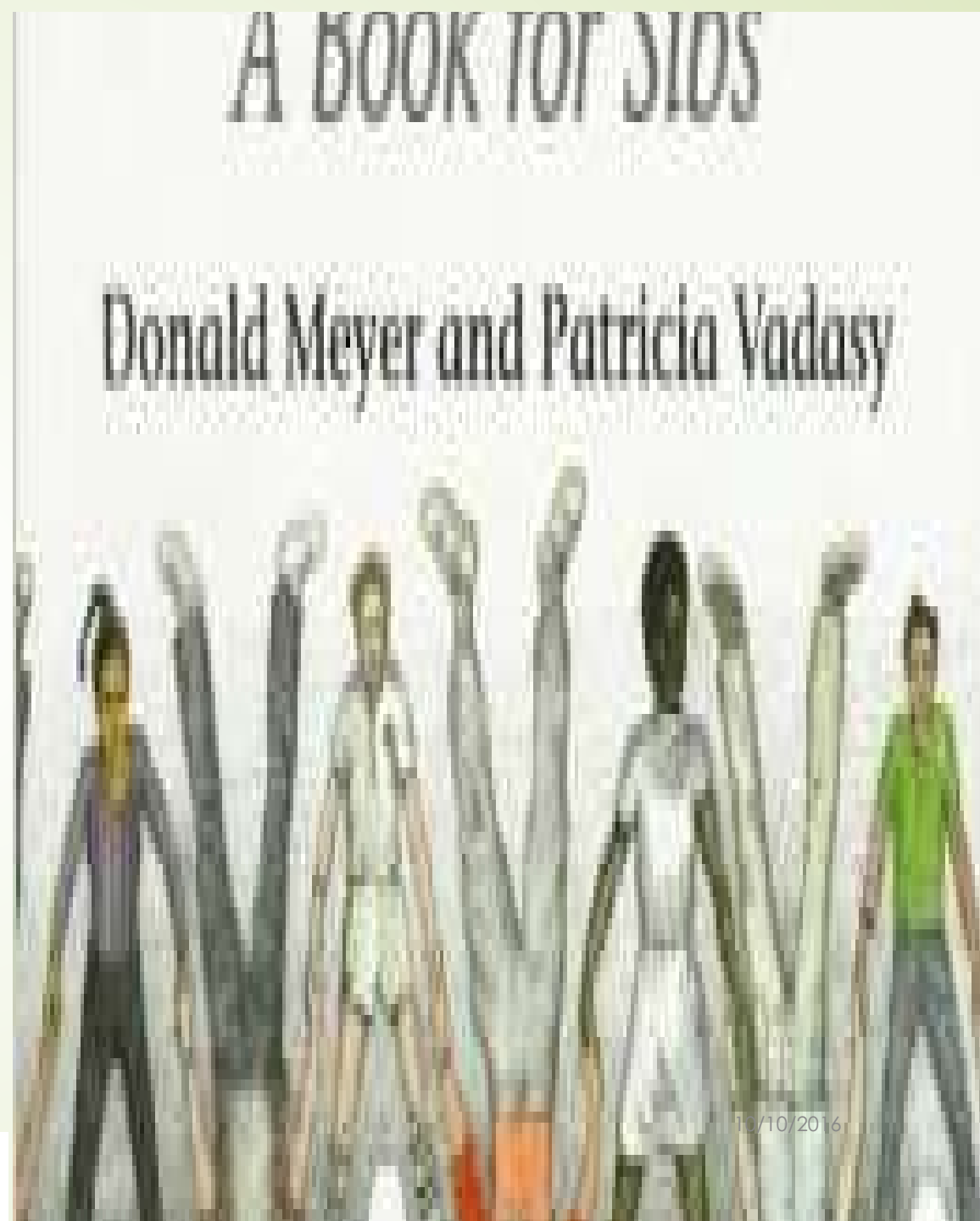
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10/10/2016

- ***Living with a Brother or Sister with Special Needs*** focuses on the intensity of emotions that brothers and sisters experience when they have a sibling with special needs, and the hard questions they ask:
  - What caused my sibling's disability?
  - Could my own child have a disability as well?
  - What will happen to my brother or sister if my parents die?
- Written for young readers, the book discusses specific disabilities in easy to understand terms. It talks about the good and not-so-good parts of having a brother or sister who has special needs, and offers suggestions for how to make life easier for everyone in the family.

The book is a wonderful resource, not just for siblings and their parents but also for teachers and other professionals who work with children with special needs. This revised and updated edition includes new sections on attention deficit hyperactivity disorder, fetal alcohol syndrome, fragile X syndrome, traumatic brain injuries, ultrasound, speech therapy, recent legislation on disabilities, and an extensive bibliography.



# When Are SibShops Offered?

- St. Johns County – currently planned
  - 9:00 AM – 12:00 PM
    - Friday - February 17, 2017  
Palencia Elementary School
    - Monday - March 20, 2017  
Fullerwood Training Center

# How To Register?

- Registration is required
  - Want to reserve a spot
  - There are 12 spots available
  - <http://stjohnssibshops.eventbrite.com>