

AUCD

ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES

RESEARCH, EDUCATION, SERVICE

Brighter Tomorrows: Supporting Families with Accurate Information About Down Syndrome RTOI WEBINAR

December 9, 2008

Presented by AUCD and supported by Cooperative Agreement from the
National Center on Birth Defects and Developmental Disabilities
(NCBDDD) at Center for Disease Control and Prevention (CDC)



Webinar Agenda

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- I. Welcome & Introduction – Sue Lin, MS Project Director,
AUCD-NCBDDD Cooperative Agreement
- II. Presentation
 - **Brighter Tomorrows: Supporting Families with Accurate Information About Down Syndrome** – Harold Kleinart, EdD and Carol Lunney, PhD Interdisciplinary Human Development Institute, University of Kentucky
- III. Discussant
 - Madeline Will, Vice President of Public Policy
National Down Syndrome Society
- IV. Question and Answer

Overview: AUCD-NCBDDD Cooperative Agreement

- Strengthen the nation's capacity to carry out public health and disability activities
- Foster collaborations among AUCD, its network (UCEDD, LEND, DDRC) members, and NCBDDD
- Provide technical assistance to State Disability and Health Grantees
- Enhance the capacity of states and creating collaborative systems change in the early identification, assessment, service coordination for children with autism spectrum disorder and related disabilities through Act Early Regional Summits
- Strengthen expertise in the fields of birth defects and developmental disabilities through training of professionals in public health and related fields.
- Facilitate a wide range of research, education, and dissemination activities.



Research Topics of Interests (RTOI)

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RTOI are specific research area of significance identified by scientists at NCBDDD, CDC. Past RTOI projects have focused on the following areas:

- Health Communication and Education
- Prevention of Secondary Conditions
- Healthcare Cost Analysis
- Quality of Life Studies
- Developmental Factors and Outcomes
- Health Promotion Interventions
- Co-Morbidity Prevalence Studies



Specific disabilities areas include: autism, Down syndrome, Duchenne muscular dystrophy, epilepsy, Fragile X syndrome, hearing loss, fetal alcohol syndrome, spina bifida, and Tourette syndrome.

Presenters and Discussant

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Harold Kleinart, EdD
Interdisciplinary
Human Development
Institute, University of
Kentucky



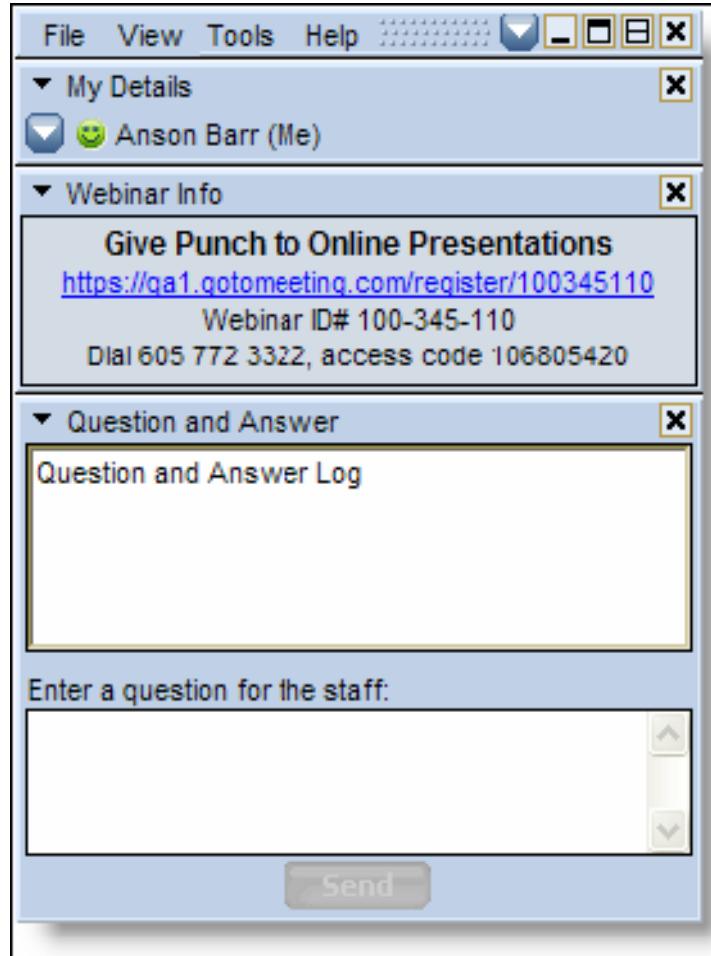
Carol Lunney, PhD
Interdisciplinary Human
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University of Kentucky



Madeline Will, Vice
President of Public
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National Down
Syndrome Society

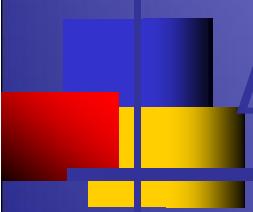
Webinar Guidelines

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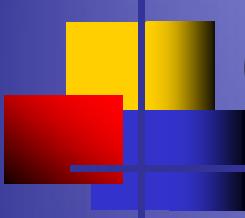
- All participants lines will be MUTED during the presentation
- Operator will facilitate the Q&A session
- Participants may submit questions online during presentation through Go To Webinar text box at any time

Sample webinar screen



Brighter Tomorrows: Diagnosing Down Syndrome From the Beginning

Harold L. Kleinert, Ed.D.
Carol A. Lunney, Ph.D
AUCD Webinar
December 9, 2008

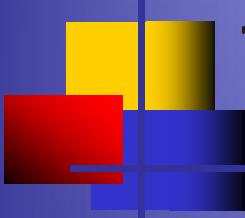


Our Project

- *Brighter Tomorrows* –NCBDDD-AUCD RTOI Project to train resident physicians to provide accurate, supportive information to families upon the initial diagnosis of Down syndrome (both pre and post-natally).
 - Originally funded in 2003
 - Funded to create web-based tool in 2007.

Catalysts for Brighter Tomorrows

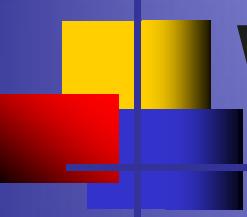
- Negative stereotypes of persons with Down syndrome (DS) persist despite tremendous gains in life outcomes and societal inclusion.
- Physicians receive little training in DS, the meaning of screening results, or in how to deliver challenging diagnoses such as DS. They often present only the “negatives” or incomplete information.
- Recent advances in early screening.



The Importance of the Project

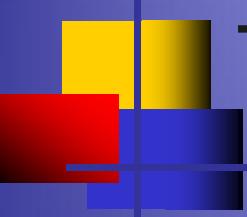
- What the Research Shows:
 - Physicians rarely receive training related to communicating a diagnosis of DS (Cleary-Goldman et al., 2006), although communications skills training is an essential part of medical education (Accreditation Council for Graduate Medical Education, 2006).
 - Families want and need physicians to provide balanced and accurate information, but report they receive incomplete and/or primarily negative information for both prenatal and newborn diagnoses (Skotko, 2005a & b).

Understanding Complexities... What We Don't Know...



Have Residents Received Training:

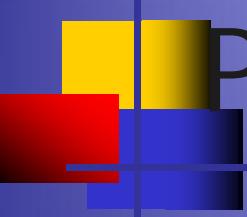
- About *DS itself*
- About *screening and diagnostic testing*
- In delivering *challenging diagnoses* and "*unexpected*" news (Ambiguous situations in which the "best responses" depend upon contextual variables, including the emotions of the patient)
- Their *own* perceptions of individual differences



Understanding Complexities - Teaching Beyond Didactics...

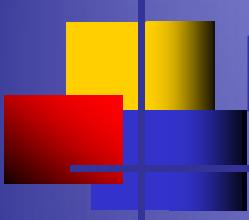
Educational Delivery to Adult Learners –

- Situational simulations
- Modeled behavior
- Multimedia components
- Learner interaction – “being brought into the situation” to decide for oneself
- Content based on input from stakeholders (physicians, parents, educational specialists)



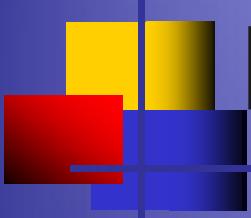
From Both Sides Now: A Physician's Dual Perspective

- “I now understand even more clearly that it is imperative that the counseling of those who wish to be screened and tested include all aspects of raising a child with Down syndrome, not just the negative ones....(F.H. Boehm, *Obstetrics and Gynecology*, 2007)



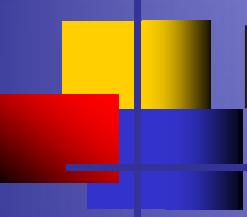
History of Brighter Tomorrows

- An expert medical/parent team convened to plan, design, and produce an interactive CD with Modules on *in utero* and newborn diagnoses.
- The resulting product included virtual patient/doctor interactions, information points, both open-ended and multiple choice “decision points”, and additional resources.



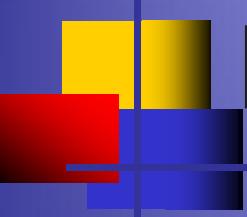
History of Brighter Tomorrows

- The product was pre-tested with 4th year Peds and OB/GYN residents at one university
- Pre-post tests were administered to 30 1st through 3rd year residents at one university.
- Effectiveness was evaluated by change in knowledge and comfort levels as measured on pre- and post tests of each.



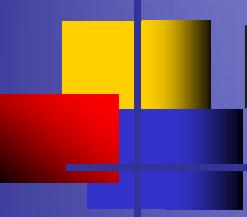
Results of Newborn Module Effectiveness Study

- *Knowledge measure* included 15 multiple choice questions on genetics, communicating a diagnosis to families, secondary conditions, and life outcomes. Pre-post differences were significant (<.001).
- *Attitudinal scale* consisted of a situational inventory to assess residents' perceived comfort level in dealing with difficult questions/situations involving a newborn diagnosis of Down syndrome. Pre-post differences were significant (<.001).



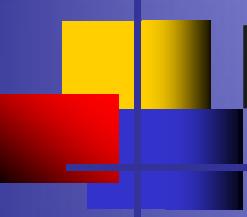
Results of Postnatal Module Effectiveness Study

- Complete results published: Ferguson, J., Kleinert, H.L., Lunney, C.A., & Campbell, L. (2006). Improving resident physicians' competencies and attitudes in delivering a postnatal diagnosis of Down syndrome. *Obstetrics and Gynecology*, 108, 898-905.



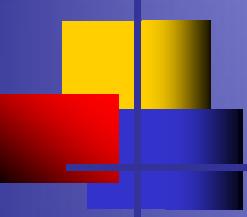
Results of Prenatal Module Effectiveness Study

- 15 multiple choice items sampled knowledge of first & second trimester screening, definitive diagnosis procedures, risk factors, and counseling approaches to delivering unexpected news. Mean improvement was 3.86 points ($SD=2.70$) ($p<.001$).
- For Module II Situational Inventory, mean improvement was also significant ($p<.001$), indicating a greater sense of comfort with potentially difficult situations in delivering a pre-natal diagnosis.



Building On Our Findings: Prenatally....

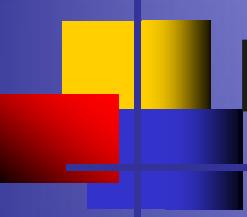
- Extent to which physicians provide up-to-date “life” knowledge about DS at key moments of prenatal patient care:
 - *What* are we screening for and *what* are we testing for and *not* just the risks and limitations of those tests...
 - A critical element of Informed Consent.



How Patients Perceive This Information...

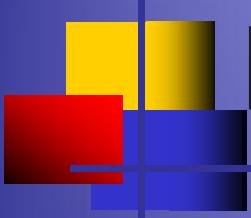
Do physicians have accurate knowledge about the risks & benefits of current screening tests:

- Potentially strong anxiety reactions to being at higher risk
- And a potentially untenable position for some women (Kuppermann et al., 2006)



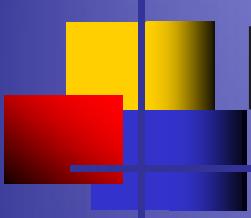
Pre-Natal Diagnosis -Are Physicians Prepared To Present All Options...

- The possibility of *adoption* - In a survey of individuals waiting to adopt a child with Down syndrome (N = 72), only one individual had learned of this option from a medical professional (Lindh, Steele, Page-Steiner, & Donnenfeld, 2007).



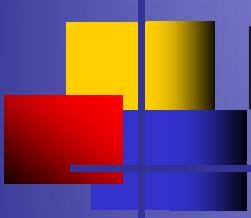
Evidence Based Practice

- Using language patients can understand,
- Stressing the voluntariness of screening and diagnostic testing
- Understanding the “psychological confusion, anxiety, and decision-making concerns that accompany them” (Zindler, 2005).
- Acknowledging that physicians often approach the “decision-making process” from a different orientation than patients (Hunt et al., 2005)



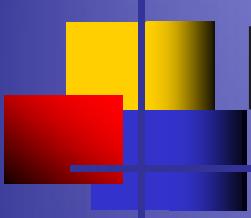
Delivering a Diagnosis...

Evidenced-based tools for physicians and health care providers that model how to deliver a diagnosis (both prenatally and postnatally), including the communication competencies, the content and timing, the setting, and the inclusion of both partners.



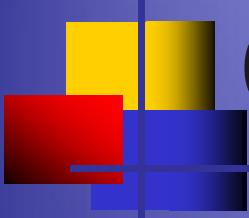
Delivering a Diagnosis...

Effective strategies to ensure that physicians and other health care providers offer their patients contacts to parent support groups and referral to other parents at the point of initial diagnosis (Skotko, 2005b).



Delivering a Diagnosis...

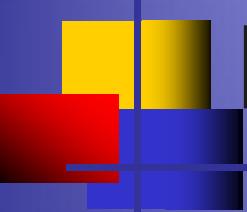
Ensuring that educational materials developed to teach physicians and health care providers how to communicate with families are created in *collaboration* with families, and when possible, with individuals with Down syndrome themselves.



Our Current Project...

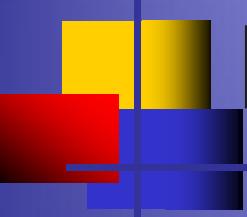
A 2nd RTOI (2007) to increase accessibility of the tool and to reflect the most current knowledge of families and professionals.

- *Web-Based Tutorial* offers pre and post-natal cases that can be accessed alone or together
- *Refresher Tool* for practicing physicians provides key review points.
- *Family Version* in English and Spanish



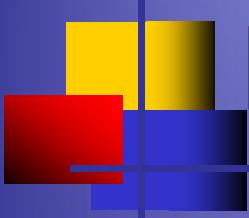
Key Tutorial Components: Brighter-Tomorrows.org

- Interactive Case: Prenatal Diagnosis
- Interactive Case: Newborn Diagnosis
- Resource Documents
- *Life Glimpses* of Children and Young Adults
- See www.Brighter-tomorrows.org



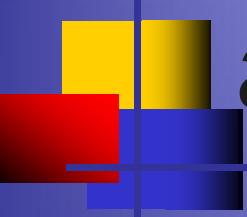
Examples of Resource Documents...

- Altered Expectations
- Early Intervention
- Medical Concerns
- Newborn and Prenatal Brochures for Families (printable)
- Annotated Bibliography



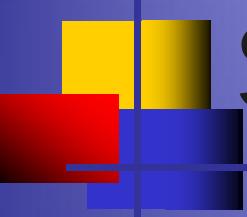
Refresher Tool

- Also Available at
www.brighter-tomorrows.org
- Provides quick review of key points, with selected videos, and the ability to link to the full tool
- User-driven: Review only what you need to when you need it!



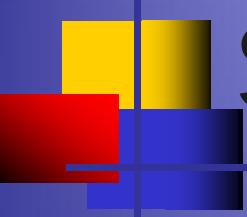
Effectiveness Study – Spring and Summer 2008

- 16 residency programs (10 pediatric and 6 OB/GYN) from across the country participated with an N of 133 residents)
- We used measures of content and attitude similar to those used in the first study
- One difference: we examined differences in discomfort levels and change depending upon the *ambiguity* or *certainty* (a clear-cut response) of the hypothetical situation.



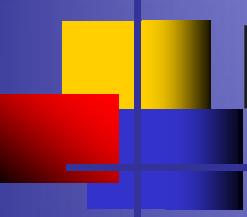
Results of 2008 Effectiveness Study

- Accepted for poster sessions at the *Society for Maternal and Fetal Medicine* and the *American College of Obstetricians and Gynecologists*
- Accepted for presentation at the *Southern Society for Pediatrics Research*
- Article submitted to *American Journal of Obstetrics and Gynecology*
- Article in process specific to pediatrics results



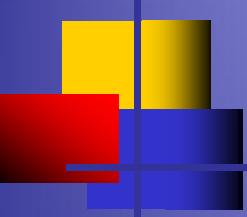
Results of 2008 Effectiveness Study

- Residents made equivalent knowledge gains in their *non-specialty* area as they did in their own discipline - true for both pediatric and OB/GYN residents
- Regardless of one's specialty area, the importance of understanding the whole experience of the patient – residents saw the full content as important to learn



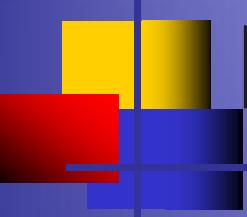
Perceptions of Ambiguous vs. Non-Ambiguous Situations

- Evidence of *greatest* gains in dealing with *ambiguous* situations as opposed to those in which a clear answer can be provided:
 - *Ambiguous* Item: The mother comes into your office in tears because she overheard a colleague of yours say that "Down syndrome children never amount to anything."
 - *Unambiguous* Item: The parents are troubled about the increased chance of heart problems and want advice on what to do.



When Medical Knowledge By Itself is Not Enough...

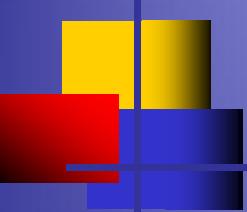
- *Ambiguous* situations require a deeper sense of what the patient is experiencing;
- Knowledge of life outcomes and family impact that transcends purely medical content;
- Teaching residents to respond to these situations cannot be conveyed by purely didactic learning models (Knowles, 1990).



BT Family Version - *no hyphen*

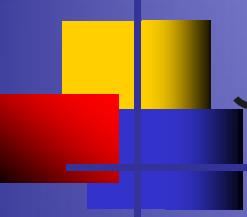
Brightertomorrows.org

- English & Spanish
- Video-anchored Q & A
- Life Glimpses
- Receiving the News
- Resources for Families
- Survey



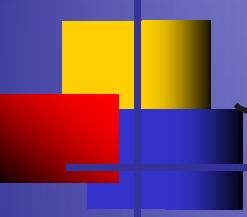
Survey Results of Family Version

N = 34	Mean (5 = very helpful)	Median	% "Helpful or Very Helpful"	% Quite or Very Easy
Q & A	4.56	5	93%	NA
Resources	4.51	5	93%	NA
Life Glimpses	4.80	5	97%	NA
Ease of Navigation	4.78	5	NA	100%



Family Comments About Their Journey

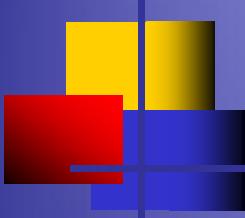
- I value the honesty of doctors but also the support.
- I value nothing about the doctor's interaction that morning.
- A pediatrician expressed it best for us, "Congratulations on your son! I am sorry for the added concern." There were many concerns (still are), but our son has always been a blessing.



Family Comments About Their Journey and Brighter Tomorrows

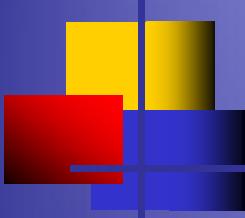
From a 26-35-year old father:

- “Even though it feels like we have come a long way since that day (8 months ago when our daughter was born), this site provided some info and stories in such a touching and sensitive way. I cannot thank you enough for this site...”



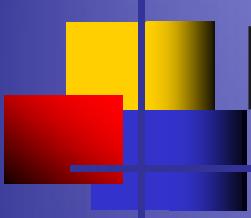
Next Steps

- ACOG is considering use of Brighter Tomorrows for CME's.
- We have approached the AAP for consideration of CME's.
- We have approached the *Council on Residency Programs in Obstetrics and Gynecology (CREOG)* and are approaching the *Association of Pediatric Program Directors (APPD)* for adoption into their curricula.



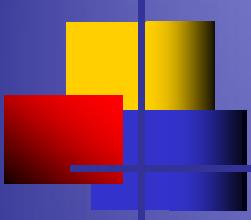
Next Steps

- As regulations are developed for the *Prenatally and Postnatally Diagnosed Conditions Awareness Act* (P.L. 110-374), BT is one evidenced-based tool for training physicians.
- Brighter Tomorrows *Family Version* will be offered for inclusion on advocacy Websites such as NDSS and NDSC.



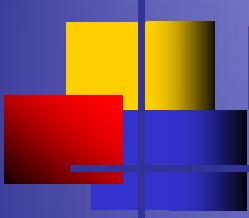
From Both Sides Now...

- “As we enter a world in which more genetic information will be available for us to consider in selecting a “perfect” child, I hope we have room in our hearts for those like Seth who are challenged and different, because challenged and different can still be perfect.”
(Boehm, *Obstetrics and Gynecology*, 2007)



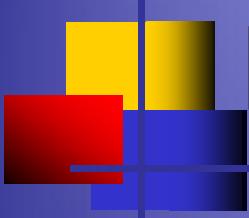
Interacting with the Tools

- Physicians Version:
 - www.brighter-tomorrows.org
- Family Version:
 - www.brightertomorrows.org



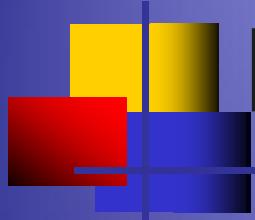
References

- The Accreditation Council for Graduate Medical Education. Core Competencies. (2006). Available at:
http://www.acgme.org/acWebsite/RRC_280/280_coreComp.asp. Retrieved September 16, 2008.
- Boehm, F.H. (2007). Having a perfect child. *Obstetrics and Gynecology*, 109, 444-445.
- Cleary-Goldman , J., Morgan, M.A., Malone, F.D., Robinson, J.N., D'Alton, M.E., & Schulkin, J. (2006). Screening for Down syndrome: Practice patterns and knowledge of obstetricians and gynecologists. *Obstetrics and Gynecology*, 107, 11-17.
- Ferguson, J., Kleinert, H.L., Lunney, C.A., & Campbell, L. (2006). Improving resident physicians' competencies and attitudes in delivering a postnatal diagnosis of Down syndrome. *Obstetrics and Gynecology*, 108, 898-905.
- Hunt, L.M., deVoodg, K.B., & Castaneda, H. (2005). The routine and traumatic in prenatal genetic diagnosis: Does clinical information inform patient decision-making? *Patient Education and Counseling*, 56, 302-312.



References (cont)

- Knowles, M.S. (1990). Fostering competence in self-directed learning. In: R. M. Smith & Associates (Eds.). *Learning to learn across the life span (1st ed.)* (p. 123-136). San Francisco: Jossey Bass, 1990.
- Kuppermann, M., Learnman, L.A., Gates, E.G., Gregorich, S.E., Nease, R.F., & Lewis, J. (2006). Beyond race or ethnicity and socioeconomic status: Predictors of prenatal testing for Down syndrome. *Obstetrics and Gynecology*, 107, 1087-1097.
- Lindh, H.L., Steele, R., Page-Steiner, J., & Donnenfeld, A.E. (2007). Characteristics and perspectives of families waiting to adopt a child with Down syndrome. *Genetics in Medicine*, 9, 1-6.
- Skotko, B.G. (2005a). Prenatally diagnosed Down syndrome: Mothers who continued their pregnancies evaluate their health care providers. *American Journal of Obstetrics and Gynecology*, 192, 670-677.
- Skotko, B.G. (2005b). Mothers of children with Down syndrome reflect on their postnatal support. *Pediatrics*, 115, 64-77.
- Zindler, L. (2005). Ethical decision-making in first trimester pregnancy screening. *Journal of Perinatal and Neonatal Nursing*, 19, 122-131.



Brighter Tomorrows...

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