



# completing the circle of care

care to attend

September 26 – 29, 2004  
The Carlton Hotel  
Edinburgh, Scotland

## Children's Hospice International 16th World Congress

*in partnership with*



Association for Children with Life-threatening  
or Terminal Conditions and their Families (ACT)  
*Bristol, United Kingdom*



Children's Hospice Association Scotland (CHAS)  
*Edinburgh, Scotland*



The Association of Children's Hospices (ACH)  
*Bristol, United Kingdom*



No shape better defines or encompasses nature and life. We at Children's Hospice International embrace the circle as a metaphor for children's hospice care. The child stands at the center, surrounded by family, volunteers, and devoted professionals from many disciplines.

You too are a crucial part of this circle, for we need your skills and commitment to complete the circle of care.

# Children's Hospice International 16th World Congress

## About the World Congress

The primary focus of CHI's 16th World Congress is to stimulate the development and expansion of children's hospice and palliative care worldwide. Speakers include international leaders in the care of children with life-threatening conditions and their families. Practical guidelines in the implementation of children's hospice and palliative care will be provided. Innovative programs from around the world will be featured.

## CHI Achievement Awards

In 1995, CHI established the following awards to honor their namesakes for their outstanding pioneering efforts in children's hospice care. In their honor, these awards are given to others who have made significant contributions to the field. We invite you to phone CHI at 800.2.4.CHILD or e-mail us at [info@chionline.org](mailto:info@chionline.org) for the nomination form. The deadline for submitting a nomination is July 25, 2004. For more information on these awards, go to [www.chionline.org](http://www.chionline.org).

*Charles A. Coor Award for Literature*

*Sister Frances Dominica Award for Innovative Program Development*

*Earl A. Grollman Award for Bereavement*

*Elisabeth Kübler-Ross Award for Outstanding Contribution*

*Melinda Lawrence Award for Children's Literature*

*Robert A. Milch Award for Palliative Pain and Symptom Management*

*Mattie Stepanek Champion Award*

## 16th World Congress Partners

### Association for Children with Life-threatening or Terminal Conditions and their Families (ACT)

Lizzie Chambers, Acting Chief Executive  
Bristol, England

### Children's Hospice Association Scotland (CHAS)

Agnes Malone, Chief Executive  
Children Hospice Association Scotland  
Edinburgh, Scotland

### The Association of Children's Hospices (ACH)

Barbara Gelb, B.Soc.Sc., CASS, CQSW  
Chief Executive  
The Association of Children's Hospices  
Bristol, England

### CHI's International Advisory Council

#### Stefan Friedrichsdorf, MD

Chairman, Pain and Palliative Care Service  
The Children's Hospital at Westmead  
Westmead, Australia

#### Anna Garchakova, PhD

Director, Belarussian Children's Hospice  
Minsk, Belarus

#### Ann Goldman, MB, FRCP

Consultant in Pediatric Palliative Care  
Hematology/Oncology Department  
Great Ormond Street Hospital for Children  
London, England

#### Lisbeth Quesada Tristán, MD

Director, Palliative Care and Pain Control Clinic  
National Children's Hospital  
President, Palliative Care Foundation  
San José, Costa Rica

#### Barbara Sourkes, PhD

Director, Pediatric Palliative Care Program  
Lucile Packard Children's Hospital at Stanford University  
Palo Alto, California, USA

### Keynote Speaker

#### Joseph F. O'Neill, MD, MPH

Deputy Coordinator & Chief Medical Officer  
Office of Global AIDS Coordinator  
United States Department of State  
Washington, DC, USA

# Children's Hospice International 16th World Congress

## Workshops

In-depth discussion on the broad range of issues facing pediatric hospice and palliative care providers, led by leaders in the field

## Poster Presentations

Review a variety of models and systems

## Sight-Seeing Opportunities

Site visit to Rachel House, Wednesday, September 29, 2004. Information is available upon request.

The Carlton Hotel is located in the center of historic Edinburgh, near the castle – you'll have many opportunities within walking distance!

Sight-seeing trips in and around historic Edinburgh and around the United Kingdom available through the hotel.

## Hotel Reservations

### Call

0131.472.3000 (Inside UK)

44.131.472.3000 (Outside UK)

Mention the Children's Hospice International group to receive the special congress rate

### Special Conference Rates

Single Occupancy £110.00 per person, per night

Double Occupancy £70.00 per person, per night

### The Carlton Hotel

19 North Bridge

Edinburgh, EH1 1SD Scotland

You must guarantee your reservation with a first night's deposit or a major credit card. Hotel cancellations must be received 72 hours prior to arrival.

# Preliminary Schedule

(as of June 10, 2004)

## Sunday: September 26, 2004

7:00am Breakfast

8:00am- 5:00pm Registration

12:00pm – 5:00pm Exhibitions

1:00pm – 3:00 pm Poster Sessions

*Aromatherapy Works, I've Got Proof*; Jackie Farnell, LMT, LE

*A Community Hospice/Academic Collaborative Program for Pediatric End-of-Life Care*; Brian Carter, MD, FAAP; John Mulder, MD

*The Cocoon Project- Transformation of a Hospital Room to Home Environment for Terminally Ill Children*; Brian Greffe, MD; Nancy King, MSN, RN, CPNP

*Developing a Pediatric Community Coalition*; Shannon Bruggen, MSW, LCSW; Betsy Clark, RN, CHPN

*Enhancing Care Coordination for Children with Life-threatening Conditions: How does Information Technology fit into a Military PACC model?*; Cheryl Naulty, MD; Karen-Ann Lichtenstein, MA; Carol Marsiglia, MSN, CCM

*Making "Friends": Engaging Both Business and Community in True Partnerships*; Gail Hessel

*Volunteer Chaplaincy — Opening the Door to Pastoral Care by Community Involvement*; Michael Jackson, MDiv, A.B.

*Pediatric Consortium: Coordinating a Community in Pediatric Care* Sandy Macomber, MSW

*Pediatric Palliative Care in Utah— A Coalition in Motion*; Lisa Ann Morrise, MA  
*Whose Rights? Is there a Wrong? Defining What is in the Child's Best Interest*; Emmie Gardner, LCSW, MSW

5:30pm – 7:00pm Documentary Screening and Discussion:  
*Making Every Moment Count*  
Hosted by Leora Kuttner, PhD, Clinical Professor

## Monday: September 27, 2004

7:00am Breakfast

7:00am – 5:00pm Registration

8:30am Welcome and Introductions

Malcolm Chisholm (invited), Scottish Minister of Health and Community Care

Ann Armstrong-Dailey, Children's Hospice International

Lizzie Chambers, Association for Children with Life-threatening or Terminal Conditions and their Families

Barbara Gelb, The Association of Children's Hospices

Agnes Malone, Children's Hospice Association Scotland

8:45am – 11:15am Keynote Address & Plenary Session  
Highland Suite

**Keynote Address:** *Children with HIV AIDS: A Global Perspective*  
Joseph F. O'Neill MD, MPH, Deputy Coordinator and Chief Medical Officer,  
Office of Global AIDS Coordinator, United States Department of State

### Plenary Session

*A Parent's Perspective*; Susan H. Green

# World Congress Faculty

(as of June 10, 2004)



**Clarke P. Anderson, MD**, Assistant Professor of Clinical Pediatrics, Division of Hematology/Oncology, Children's Hospital of Los Angeles, Los Angeles, California, USA

**Bob A. Archuleta, MD, FAAP, FAAHPM**, Medical Director, Noah's Children Hospice and Palliative Care, Richmond, Virginia, USA

**Ann Armstrong-Dailey**, Founding Director, CEO Children's Hospice International, Alexandria, Virginia, USA

**Laurie Badzek, MS, RN, JD, LLM**, Project Leader, West Virginia Pediatric Palliative Care Network, Morgantown, West Virginia, USA

**Marina A. Bialik, MA, PhD**, Magic Key, Roslindale, Massachusetts, USA

**Myra Bluebond-Langner, PhD**, Professor of Anthropology and Director of the Center for Children and Childhood Studies, Rutgers University, Camden, New Jersey, USA

**Chris Brown, MS, CCLS**, Director, Child Life, The Children's Hospital of Philadelphia, Philadelphia, Pennsylvania, USA

**Erica Brown, MA, MEd**, Head of Research and Development, Acorns Children's Hospice, Birmingham, England

**Shannon Bruggen, MSW, LCSW**, Coordinator, Pediatric Community Alliance, Hospice and Palliative CareCenter, Winston-Salem, North Carolina, USA

**Brian Carter, MD, FAAP**, Associate Professor of Pediatrics, Department of Pediatrics, Vanderbilt University Medical Center, Nashville, Tennessee, USA

**Lizzie Chambers**, Acting Chief Executive, Association for Children with Life-threatening or Terminal Conditions and their Families, Bristol, England

**Eileen R. Chisari, RN, BSN, MsEd, MS, LNHA**, Administrator, Vice President of Inpatient Programs, St. Mary's Healthcare System for Children, Bayside, New York, USA

**Betsy Clark, RN, CHPN**, Professional Development Coordinator, Hospice and Palliative CareCenter, Winston-Salem, North Carolina, USA

**Alison Closs, MA, MEd**, Senior Lecturer, University of Edinburgh, Edinburgh, Scotland

**Teresa M. Conte, MSN, CRNP**, Staff Nurse, Leadership Level Three, Division of Oncology, The Children's Hospital of Philadelphia, Philadelphia, Pennsylvania, USA

**Finella Craig, MBBS, BSc, MRCP**, Pediatric Palliative Care Consultant, Great Ormond Street Hospital for Children, London, England

**Tomasz Dangel, MD, PhD**, Assistant Professor, Department of Palliative Care, Institute of Mother and Child, Warsaw, Poland

**Angela Reed Demanelis, BS, MPA**, Project Manager, West Virginia Pediatric Palliative Care Network, Morgantown, West Virginia, USA

**Erin M. Denholm, RN, MSN**, Sr. Vice President, Centura Home Care and Hospice, Denver, Colorado, USA

**Josie Dwyer, BSc**, Family Support Practitioner, East Anglia's Children's Hospices, Cambridge, England

**Jackie Farnell, LMT, LE**, President, Scents-ible Solutions, Aiken, South Carolina, USA

**Stefan J. Friedrichsdorf, MD**, Fellow in Pediatric Palliative Care, Pain and Palliative Care Service, The Children's Hospital at Westmead, Sydney, New South Wales, Australia

**Anna Garchakova, PhD**, Director, Belarussian Children's Hospice, Minsk, Belarus

**Emmie Gardner, MSW, LCSW**, Director of Hematology/Oncology/Transplant Service Line, Primary Children's Medical Center, Salt Lake City, Utah, USA

**Barbara Gelb, B. Soc. Sc., CASS, CQSW**, Chief Executive, The Association of Children's Hospices, Bristol, England

**Ann Goldman, MB, FRCP**, Pediatric Palliative Care Consultant, Hematology/Oncology Department, Great Ormond Street Hospital for Children, London, England

**Brian Greffe, MD**, Pediatric Oncologist, Executive Director Colorado CHI PACC, The Children's Hospital, Denver, Colorado, USA

**Susan H. Green**, Kingslaw House, Fife, Scotland

**Richard Hain, MBBS, MSc, MD, MRCP(UK), FRCPC, Dip Pall Med**, Senior Lecturer, Department of Child Health, University of Wales College of Medicine, Vale of Glamorgan, Wales, England

**Gail Hessel, RN**, Hospice Manager, Very Special Kids, Malvern, Victoria, Australia

**Eve Herd**, Quality Assurance Coordinator, The Association of Children's Hospices, Bristol, England

**Jenny L. Hynson, MBBS, FRACP**, Consultant Pediatrician, Victorian Pediatric Palliative Care Program, Royal Children's Hospital, Melbourne, Victoria, Australia

**Michael G. Jackson, MDiv, AB**, Interfaith Chaplain, Director of Pastoral Care, Primary Children's Medical Center, Salt Lake City, Utah, USA

**Alan Johnson, BA, MDiv**, Staff Chaplain, The Children's Hospital, Denver, Colorado, USA

**Nancy King, MSN, RN, CRNP**, Inpatient Butterfly Coordinator, The Children's Hospital Butterfly Program, Denver, Colorado, USA

**Leora Kuttner, PhD**, Clinical Professor, Pediatric Department, University of British Columbia, Vancouver, British Columbia, Canada

**Karen-Ann Lichtenstein, MA, LASW**, Executive Director, The Coordinating Center, Millersville, Maryland, USA

**Jill Macgregor**, Play Program Coordinator, Royal Hospital for Sick Children, Edinburgh, Scotland

**Sandy Macomber, MSW**, Children & Teens Program Coordinator, Hospice of Southwest Florida, Bradenton, Florida, USA

**Agnes Malone**, Chief Executive, Children Hospice Association Scotland, Edinburgh, Scotland

**Carol A. Marsiglia, MSN, RN, CCM**, Division Director for the ACCESS Division, The Coordinating Center, Millersville, Maryland, USA

**Sister Joan Marston**, The St. Nicholas Children's Hospice, Hospice Palliative Care Association of South Africa, Bloemfontein, Free State, South Africa

**Jennie McDowall, BA**, Projects Officer, Help the Hospices, London, England

**Kim Mooney-Doyle, RN, BSN, CPON**, Staff Nurse, Leadership Level Three, Division of Oncology, The Children's Hospital of Philadelphia, Philadelphia, Pennsylvania, USA

**Lisa Ann Morrise, MA**, Outreach and Marketing Coordinator, Promoting HOPE for Utah Children (CHI PACC), Utah Department of Health, Salt Lake City, Utah, USA

**John Mulder, MD**, Vice President of Medial Services, Alive Hospice, Nashville, Tennessee, USA

**Cheryl M. Naulty, MD**, Medical Director/EFMP & EDIS, Principal Investigator and Project Director CHI PACC, Walter Reed Army Medical Center, Department of Pediatrics, Washington, DC, USA

**Joseph F. O'Neill, MD, MPH**, Deputy Coordinator & Chief Medical Officer, Office of Global AIDS Coordinator, United States Department of State, Washington, DC, USA

**Graham Perolls, OBE, AIL**, Executive Director, Hospice of Hope Romania, Kent, England

**Chacy R. Sanfilippo, MEd**, Family Support Coordinator, Ronald McDonald House, Winston-Salem, North Carolina, USA

**Claudia Schmitt, MDiv**, Staff Chaplain, The Children's Hospital, Denver, Colorado, USA

**Rosalind Scott, Dip. Society of Radiographers-Therapy, Dip. Society of Radiographers-Diagnostic**, Head of Voluntary Services, Children's Hospice Association Scotland, Edinburgh, Scotland

**Jessica Sievers**, Hastings, Minnesota, USA

**Lisa Sievers**, Foster and Adoptive Parent, Hastings, Minnesota, USA

**Roger Sievers**, Hastings, Minnesota, USA

**Mildred Solomon, EdD**, Associate Clinical Professor of Social Medicine and Anesthesia, Harvard Medical School, Vice President, Education Development Center, Inc., Newton, Massachusetts, USA

**Barbara M. Sourkes, PhD**, Kriewall-Haehl Director, Pediatric Palliative Care Program, Division of Critical Care, Lucile Packard Children's Hospital at Stanford, Stanford, California, USA

**Paula Taylor, RPh, MD**, Associate Medical Director, Kanawha Hospice Care, Inc., Cross Lanes, West Virginia, USA

**Anne Tournay, MB, BS, MRCP**, Clinical Assistant Professor, Division of Child Neurology, University of California, Irvine, Co-Medial Director, Trinity Kids Care, Torrance, California, USA

*The Child's Experience of Life-threatening Illness*; Barbara Sourkes, PhD

*I want to Live until I don't want to Live Anymore: Involving Children with Life-limiting Illness in Medical Decisions*

Myra Bluebond-Langner, PhD

11:15am – 11:30am Morning Break

11:30am – 12:30pm Concurrent Sessions 1

A. *Communication Panel:*

*Communicating Comfort When you are Uncomfortable: How to Teach and Learn Essential Communication Skills*; Teresa Conte, MSN, CRNP; Kim Mooney, RN, BSN

*Delivering Difficult News: A Protocol for Healthcare Professionals*  
Chacy Sanfilippo, MEd; Shannon Bruggen, MSW, LCSW

B. *Therapeutic Play Interventions with Ill or Grieving Children*  
Chris Brown, MS, CCLS; Jill MacGregor

C. *Practical Symptom Management*; Finella Craig, MBBs, Bsc, MRCP

D. *The Withholding and Withdrawing of Artificial Nutrition for Infants and Children at the End-of-Life: A Point Counterpoint Discussion*; Brian Carter, MD, FAAP; John Mulder, MD

12:30pm – 2:00pm Awards Luncheon

2:00pm – 3:30pm Concurrent Sessions 2

A. *Expressive & Energy Therapy Treatment Modalities for Children with Life-limiting Illnesses and Their Families*; Eileen Chisari, RN, BSN, MsEd, LNHA

B. *Grieving and Hope: Living with the Death of your Child*  
Michael Jackson, MDiv

C. "Perspectives" Panel:

*The Circle of Care "From a Family Perspective"*; Lise, Jessica and Roger Sievers

*Shattered to Wholeness: A Man's Reality*; Alan Johnson, MDiv

D. *A Primary Care Physician's Guide to Making Pediatric Palliative Care Decisions*; Bob Archuleta, MD, FAAP

3:30pm – 3:45pm Afternoon Break

3:45pm – 5:30pm Plenary Session

Moderator: Ann Goldman, MB, FRCP

*Pain Management of Palliative Children—Novel Routes of Administration*  
Stefan J. Friedrichsdorf, MD

*Opioid Pharmacology in Pediatric Palliative Medicine*; Richard Hain, MB BS, MSc, MD, MRCP(UK), FRCPC

*Beyond Medications: Integrative Methods for Pain and Symptom Control in Pediatric Palliative Care*; Leora Kuttner, PhD

**Tuesday: September 28, 2004**

7:00am Breakfast

7:00am – 5:00pm Registration

8:30am – 9:15am Plenary Session

*Ethics in Pediatric Palliative Care*; Tomasz Dangel, MD, PhD

*Workshop on Global Networking in Children's Hospice and Palliative Care*  
Barbara Gelb, B. Soc.Sc, CASS, CQSW; Jennie McDowell, BA

*International Panel: Global Models for Pediatric Palliative Care*  
Moderator: Ann Goldman, MB, FRCP

*Providing a Continuum of Pediatric Palliative Care in Resource-poor Settings in South Africa*; Joan Marston, Sr

*Australia: Very Special Kids "Home Away from Home"*; Gail Hessel, RN

*Belarus: Using Different Models for the Creation of Palliative Care in the Republic of Belarus*; Anna Garchakova, PhD

*Romania: Developing a Children's Hospice Service in a Resource-poor Country*; Graham Perolls, OBE, AIL

*Russia: Children's Hospice Program: Moscow's Model*; Marina Bialik, MA, PhD

11:30am – 11:45am Morning Break

11:45am – 1:00pm Concurrent Sessions 3

A. *Bereavement Panel:*

*Bereavement Issues in Paediatric Palliative Care—A Community Approach*; Josie Dwyer, BSc

*Helping the Grieving Teen or Preteen: Curricula for Grief Groups*  
Sandy Macomber, MSW

B. *Living with Life's Limits: Symbols and Rituals as Transformative Experiences for Compassionate Care at Life's End*; Alan Johnson, MDiv; Claudia Schmitt, MDiv

C. *Urban and Rural Challenge Panel: Connecting Country Roads: Development of a Network to Promote Pediatric Palliative Care in a Rural Area*; Angela Demanelis, MPA; Laurie Badzek, RN, MSN, JD, LLM

*Multidisciplinary Survey of Pediatric Palliative Care: Attitudes and Experience in a Large Metropolitan Pediatric Hospital*; Clarke Anderson, MD

D. *Volunteer Development Panel:*

*Volunteering for the Future: The Impact on Young People of Volunteering in Paediatric Palliative Care*; Rosalind Scott

1:00pm – 2:00pm Lunch

2:00pm – 2:45pm Plenary Session

*Education of Children with Life-threatening Conditions*; Alison Closs, MEd

2:45pm – 3:45pm Concurrent Sessions 4

A. *Development of a Children's Hospital Based Pediatric Palliative/Hospice Care Program — The Butterfly Program/Colorado CHI PACC Experience*  
Brian Greffe, MD; Nancy King, MSN, RN, CPNP; Erin Denholm, MSN, RN

B. *Development of Clinical Pathways and Web-based Resources in Pediatric Palliative Care—Unexpected Outcome of a Project at Royal Children's Hospital, Melbourne*; Jenny Hynson, MBBS FRACP

C. *Enhancing the Quality of Experience for Ethnic Minority Families with a Life-limited Child*; Erica Brown, MA, MEd

D. *Management of Seizures in Pediatric Palliative Care*; Anne Tournay, MB, BS, MRCP

E. *Spinal Muscle Atrophy; Case Reports at End-of-Life: The Same but Very Different*; Paula Taylor, RPh, MD

3:45pm – 4:00pm Afternoon Break

4:00pm – 5:00pm Plenary Session: *Creating Resources for Professionals Panel*

*Are we getting it right? Quality Assurance for Children's Hospice Services*  
Eve Herd, BA, MEd

*Education and Training Initiatives in Pediatric Palliative Care*  
Mildred Solomon, EdD

5:00pm Closing

7:30pm Farewell Reception

**Wednesday: September 29, 2004**

9:00am – 12:30pm

Site Visit to Rachel House

# REGISTRATION

Please complete this form and mail with check to CHI, postmarked by July 25, 2004 to receive the "Early Bird" discounted fee listed below. A copy of this form also may be e-mailed to [info@chionline.org](mailto:info@chionline.org) or faxed to 703.684.0226 with a credit card number to register. *Copies of this form may be used for additional registrations.*

Mail to: Children's Hospice International • 901 N. Pitt Street, Suite 230 • Alexandria, VA 22014, USA

Cancellations must be requested in writing and post-marked no later than August 27, 2004. No phone cancellations will be accepted. An administrative fee of \$75 will be assessed on all refunds, and refunds will be mailed after the conference. No refunds after August 27, 2004.

*Please print or type*

Name		Degrees (if applicable)	
Institutional Affiliation (if applicable)		Title	
Street Address			
City/Town	State/Province	Country	Postal/Zip Code
Telephone Number (Day)	Fax	E-mail	

**Payment** (in U.S. Dollars only please) Please Check  
**Early Bird Registration** Postmarked by July 25, 2004

- Member – Early Registration  
 Non-Member – Early Registration

**Cost**  
USD \$595.00  
USD \$695.00

**Total Cost**

\_\_\_\_\_ Please circle the letter of the session you would like to attend for each of the Concurrent Sessions:

**Regular Registration** Postmarked July 26, 2004 and after

- Member – Regular Registration  
 Non-Member – Regular Registration  
 Member Day Rate /  Non-Member Day Rate

USD \$695.00  
USD \$795.00  
USD \$265.00 / USD \$295.00

\_\_\_\_\_ **Sessions 1: A B C D**  
\_\_\_\_\_ **Sessions 2: A B C D**

**Membership**

- Individual Membership  
 Institutional Membership

USD \$80.00  
USD \$350.00

\_\_\_\_\_ **Sessions 3: A B C D**  
\_\_\_\_\_ **Sessions 4: A B C D E**

**Optional Activities**

*Please indicate if you will attend any of the following:*

- Documentary Screening & Discussion, Sept. 26, 2004 *Included*  
 Evening Reception, September 28, 2004 *Included*  
 Rachel House Site Visit, Sept. 29, 2004 *Included*

**TOTAL \$** \_\_\_\_\_  
(In U.S. Dollars only please)

**Membership**

To receive membership rates for this World Congress, enclose your membership dues along with your conference registration and payment, if you are not already a current member.

*You must be a current member of one or more of the following sponsoring organizations, to receive the member discount:*

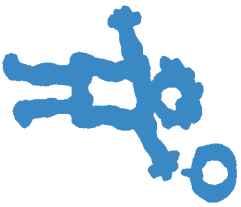
- Association for Children with Life-threatening or Terminal Conditions and their Families (ACT)
- Children's Hospice Association Scotland (CHAS)
- Children's Hospice International (CHI)
- The Association of Children's Hospices (ACH)

- A check or money order is enclosed, made payable to Children's Hospice International. U.S. Dollars only please.  
 Please charge my credit card:

Credit Card Information:  Visa  MasterCard  American Express

Credit Card Number	Exp. Date	Name on Card
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Signature



Children's Hospice International  
901 N. Pitt Street, Suite 230  
Alexandria, VA. 22314  
USA

F I R S T   C L A S S   M A I L

**Children's Hospice International**  
**16th World Congress**

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Edinburgh, Scotland

registration and preliminary program