

Global Warming in the Palliative Care Research Environment - adapting to change.

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Objectives

- 1. Reflect on the early origins of palliative care research development & advocacy.
- 1. Describe examples of palliative care research evolution - cheap & basic to expensive & sophisticated.
- 3. Reflect on what we have achieved & need to do to develop palliative care research evidence as individuals & inter-disciplinary teams.



Polar bears threatened by
record thaw across the Arctic



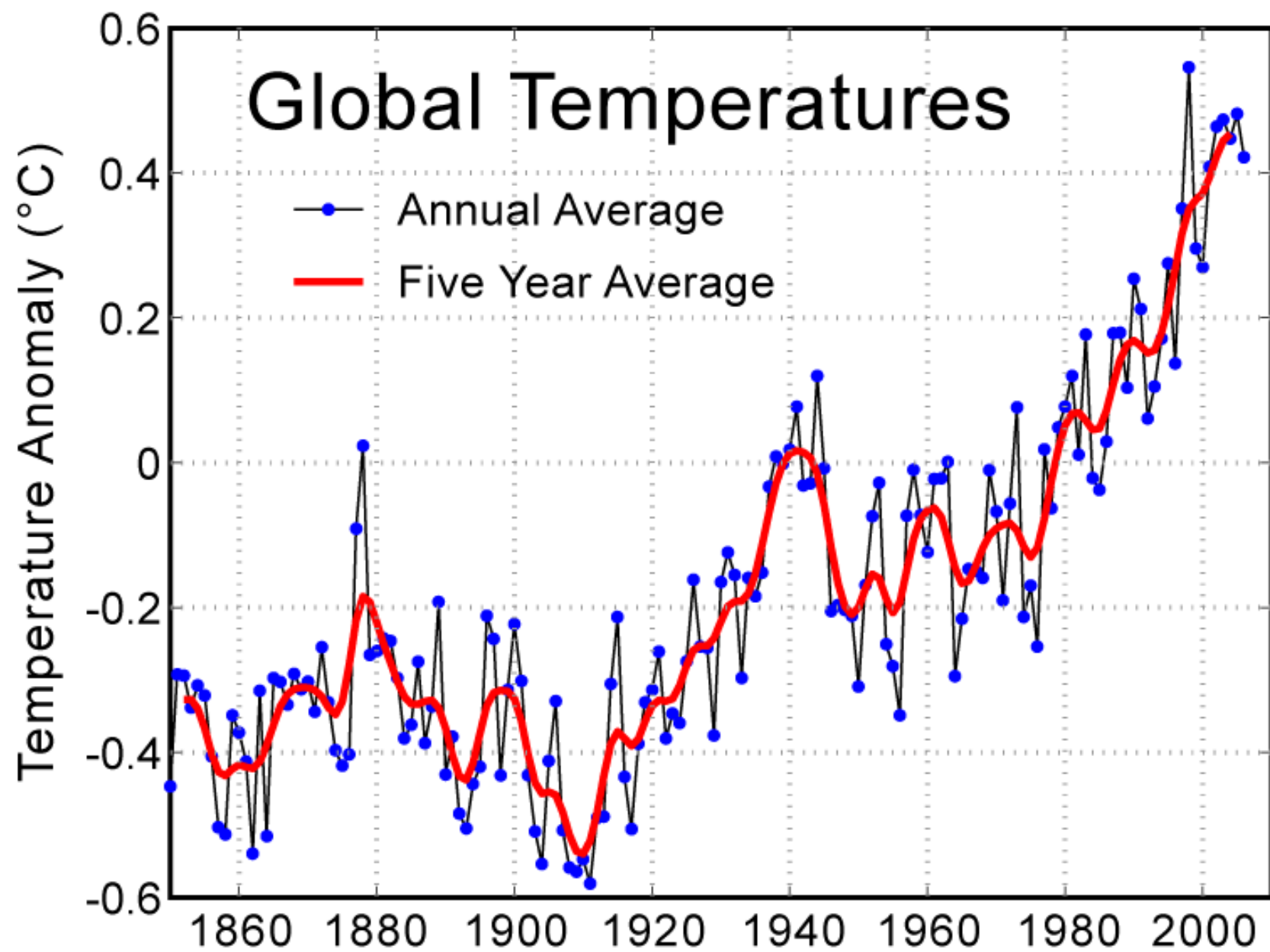
Ecosystems shift up mountainsides



China, the rousing giant of global
warming



Ocean inundates island nations



April 21, 2008
Edmonton



- Cold & difficult environment limited PC research
- Resistance to research in “vulnerable” populations
- Evidence for warming trends
- We need to adapt to challenges & opportunities

Warming Trends

- Seeds of advocacy in PC literature 1980s & early 1990s



1988 Montebello


- Sponsored by Canadian government
- Neil MacDonald report J of PC 1989
- Advocate re-allocate resources to EOL care to improve QOL without increasing costs
- Advocate NCIC improve funding for pain & symptom research
- Participant list Fainsinger before Foley

MacDonald J of PC 1992

Research – a neglected area of PC

- Need economic studies & health economist collaboration
- Develop international classification systems for cancer pain & other symptoms
- Integrate other disciplines e.g. basic scientists

Milestones

- Oct 1990 – 1st EAPC meeting in Paris
- 1991 D. Doyle – predicted the need for smaller research conferences
- 1992 G. Ford – need research for evidence “we believe is there but cannot yet provide”
- 1993 R. Twycross – need to replace anecdote & opinion with research
- Mount 1994 – recession & debt with failed advocacy  “sink like a stone beneath the waters of change that are upon us”

Kaasa et al P.M. 2006. Methodological & structural challenges in PC research: how have we fared in the last decade?

Place	Year	Oral	Poster	Number
Berlin	2000	88	112	380
Lyon	2002	69	106	525
Stresa	2004	76	211	700
Venice	2006	115	365	1000

Following needs identified:-

- 1. Academic research groups within universities
- 2. Critical mass of ID basic science & clinical research personnel
- 3. Larger, randomized, clinical multi-center studies
- 4. National initiatives targeted at developing PC research

Palliative Care Research Initiatives

- United Kingdom – June 2006 1.9 million pounds to 2 large research teams for 5 years
- European PC Research Collaborative – 6 countries represented 1.8 million Euros, fall of 2006 for 3 years
- USA – 2007 American Cancer Society & National PC Research Centre awarded \$1.5 million in research grants

Australia – August 2007

- Senator Brett Mason
- Australia National PC conference in Melbourne
- PC Clinical Studies Collaborative
- National partnerships, clinical drug studies with economic analyses
- Capacity for other PC research



Canada - May 2002

- Institute for Cancer Research Advisory Board Meeting.
- A decision was made to establish a working group for each of six priorities identified in the Delphi process.
- Neil MacDonald volunteered to lead a working group for the priority area that garnered the most votes -- Palliative Care.

Canadian Institutes of Health Research

Minister Ianno announces \$16.5 million for innovative research into palliative and end-of-life care

2004-19

MONTREAL (September 21, 2004) - The Honourable Tony Ianno, Minister of State (Families and Caregivers), Dr. Bernard Patry, Member of Parliament for Pierrefonds-Dollard, on behalf of the Honourable Ujjal Dosanjh, Minister of Health, and Dr. Alan Bernstein, President of the Canadian Institutes of Health Research (CIHR), today announced \$16.5 million in funding for the CIHR Palliative and End-of-Life Care Initiative. The announcement was made at the 15th International Congress on Care of the Terminally Ill hosted by McGill University.

"The comprehensive scope of the research being carried out makes The Palliative and End-of-Life Care Initiative a world-first. The terminally ill must be able to live with dignity, without pain, and with support for both themselves and their families," said Minister Ianno.

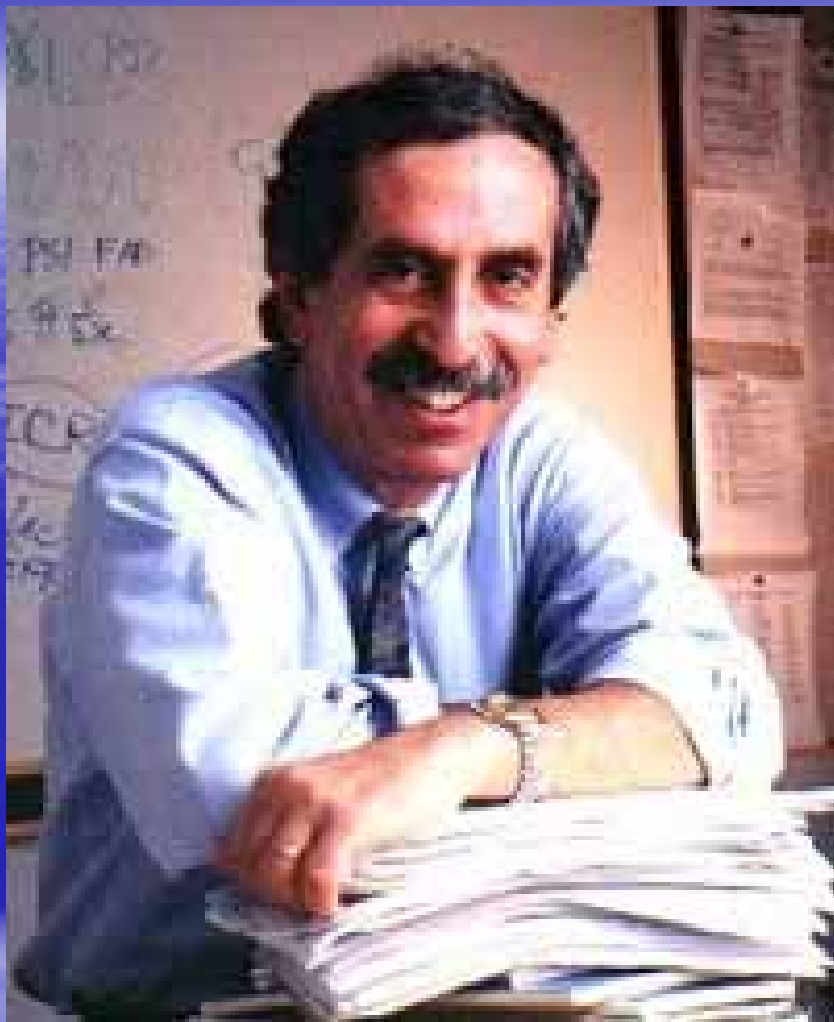
"The Government of Canada supports the priority given by CIHR to this innovative research that matters to all of us," added Dr. Bernard Patry. "This research complements the Government of Canada's recognition of the growing role of caregivers in our society."



The Honourable Tony Ianno, Minister of State (Families and Caregivers)



Dr. Neil MacDonald, Chairman of CIHR's National Working Group on Palliative Care Research; Dr. Phil Branton, Scientific Director of the Institute of Cancer Research; Dr. Bernard Patry, MP (Pierrefonds-Dollard); The Honourable Tony Ianno, Minister of State (Families and Caregivers)



Alan Bernstein, OC, PhD, FRSC
July 2000 - Inaugural President of the
Canadian Institutes of Health Research.



Prime Minister Jean Chrétien
appointed Senator Carstairs
Leader of the Government in the
Senate January 9, 2001 -
December 12, 2003

Career Transition Awards

- Career Transition Awards - attract existing researchers to palliative and end of life care as a new field of research.
- Up to \$70,000 (including fringe benefits) to support from 75% to 100% release time from teaching and administrative responsibilities, plus an additional \$10,000 research allowance for one year.

Pilot Project Grants

- Pilot project grants - intended to support innovative, high risk, pilot or feasibility research.
- Allow applicants the opportunity to try out new ideas in preparation for a future application to the regular funding programs.
- Up to \$100,000 for one year, non-renewable.

New Emerging Teams Grants (NET)

- Address the long-term issue of capacity building within the field of palliative and end of life care.
- Designed to build research capacity in new and developing areas
- Create new interdisciplinary research teams or expanding small existing teams.
- Up to \$300,000/year for five years, subject to a successful review in the third year.

New Emerging Teams Grants (NET)

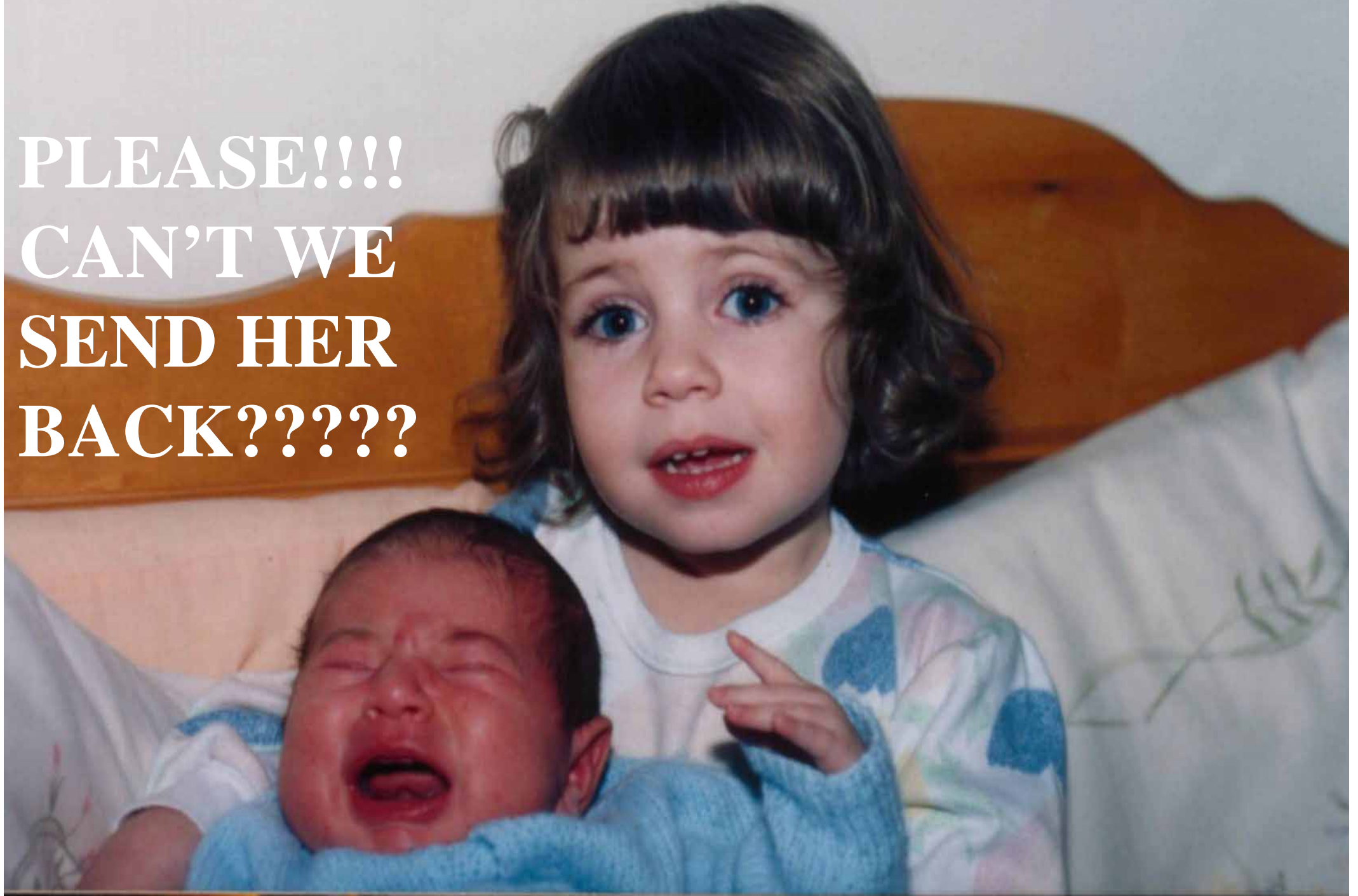
- 9/17 applications funded (52.9%)
 1. Optimizing end of life care for seniors (previous competition)
 2. Cancer-associated cachexia-anorexia Syndrome
 3. End of life care and vulnerable populations
 4. Palliative care in cross-cultural context: equitable and quality cancer care for ethnically diverse populations
 5. Developing, evaluating and implementing new interventions in palliative care

New Emerging Teams Grants (NET)

6. Improve the classification, assessment, and management of difficult cancer pain problems.
7. Understanding and improving communication and decision-making at the end of life
8. Overcoming barriers to communication through end of life and palliative transitions
9. Transitions in paediatric palliative and end of life care
10. Family care giving in palliative and end-of-life care

First world research context

**PLEASE!!!!
CAN'T WE
SEND HER
BACK?????**



3rd World

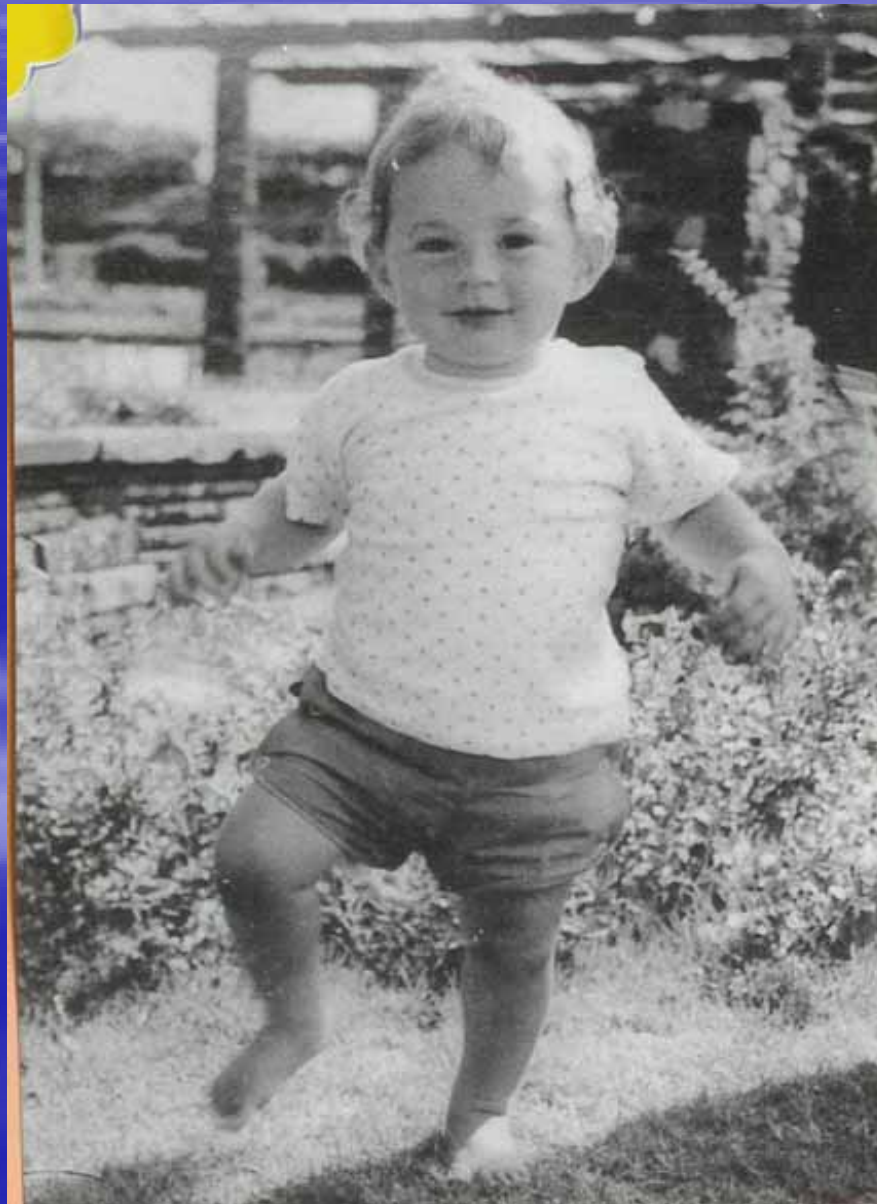


The Declaration of Venice

- EAPC & the International Association for Palliative Care – strategy to promote global research
- Focus on developing countries
- May 2006 – 4th Research Forum of the EAPC in Venice
- Meeting of 14 organizations
- All 5 continents represented

- 12 recommendations
- Document concludes with some hopes, invitations & urges
- Hope for more resources
- Invite governments, academic & professional organizations to provide support
- Urge successful palliative care research teams to twin with developing countries

Palliative Care Research Evolution - a personal experience.



Why do we need research

- PROS

- Clinical
- Education
- Administration
- Improves QOL for patients & families & health care professionals

- CONS

- No time
- Patient burden
- No money
- No expertise

SYMPTOM CONTROL
DURING THE LAST WEEK
OF LIFE ON A PCU

Fainsinger et al

J of Pall Care 1991;7(1):5-11

Background

- 100 consecutive charts of patients dying on TPCU
- Funding 0\$
- Ethics – none required
- Location – dusty archives
- Research assistant – pregnant wife
- Used recently developed ESAS

Symptom distress scores (VAS)

Day	doa	6	5	4	3	2	1	dod
Pain	35	31	29	31	31	30	29	24
Nausea	23	19	17	21	18	14	14	13
Drowsy	43	51	55	60	63	68	69	85
Sympt distress	47	49	50	51	52	52	52	52

- Demonstrated no escalation in symptom distress
- Only 16% patients required sedation (delirium 10 & pain 6)
- Concept, data accrual & submission in 3 months

WHAT MAY COMPLICATE PAIN MANAGEMENT?



- Opioid use on TPCU in 1991 MEDD > 600mg
- State these are complex patients
- How do we compare?

How can we compare?

- TNM classification for cancer
- Allows a common language for clinicians & research
- No similar classification system for cancer pain
- Difficult to compare pain treatment results

- 65 YEAR MALE CA PROSTATE/BONE METS
- PAIN LOCALISED RIGHT ARM & HIP
- MOVES COMFORTABLY
- ORIENTED & ALERT
- ON CODEINE 30 MG PRN
- STABLE MARRIAGE & HOME LIFE
- NO PSYCHIATRIC HISTORY
- NO HISTORY OF ADDICTION

OR

- 65 YR MALE CA PROSTATE/BONE METS
- BURNING/STABBING PAIN DOWN RIGHT LEG
- CANNOT MOVE WITHOUT SEVERE PAIN
- EVIDENCE OF CONFUSION

- MORPHINE INCREASED 5 MG Q4H TO 100 MG Q4H OVER 7 DAYS
- DIVORCED 3 TIMES; LIVES ALONE
- HISTORY OF DEPRESSION & SUICIDE ATTEMPTS
- LONG HISTORY OF ALCOHOL & BENZODIAZEPINE ABUSE

IASP

CANCER PAIN - PALLIATIVE CARE

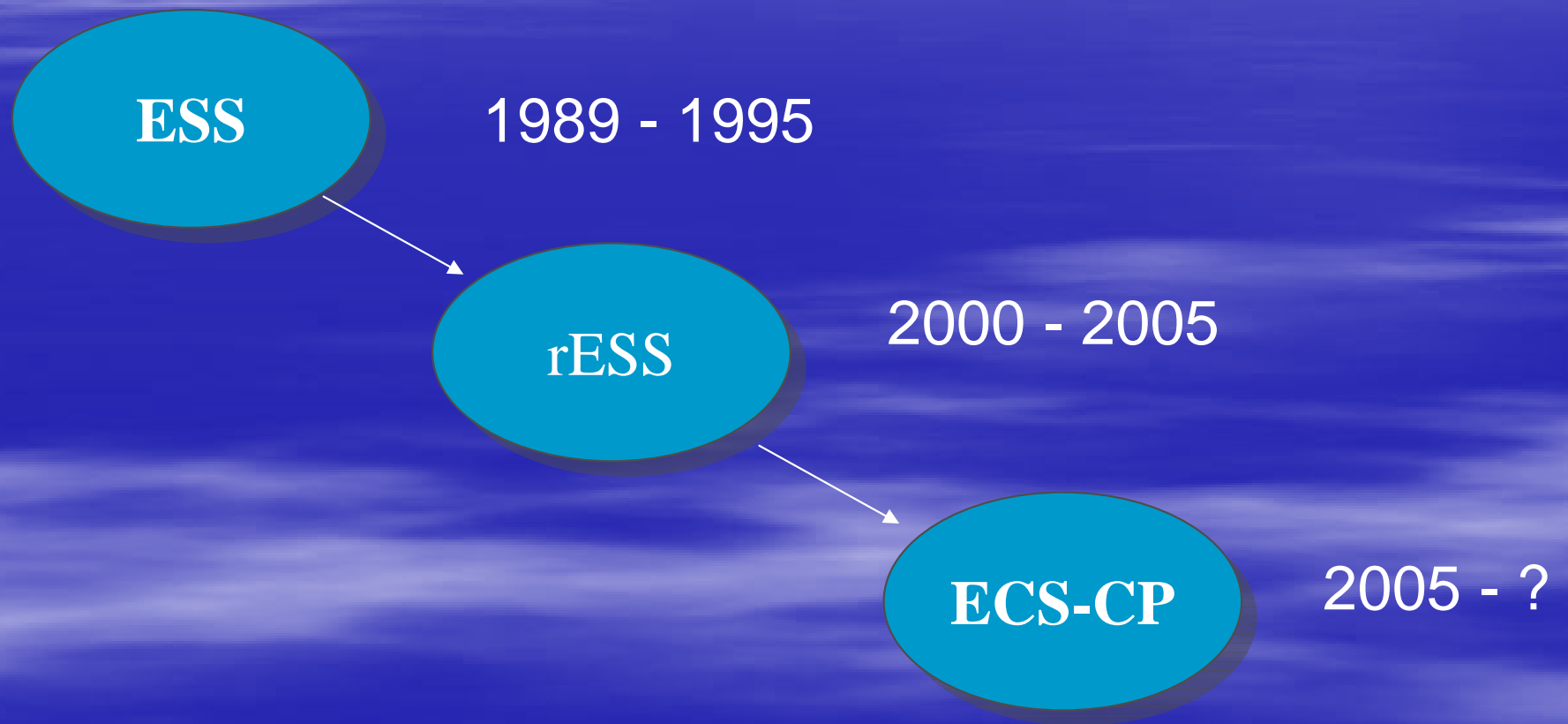
2002 – 19 ABSTRACTS

- Cancer pain 13
- Palliative Care pain 2
- Mechanism 3
- moderate/severe/intractable/refractory 1

2005 – 15 ABSTRACTS

- Cancer pain 9
(included 2 opioid rotation)
- Mechanism 6
- Pain intensity 2

Development of the Edmonton Classification System for Cancer Pain (ECS-CP)



Characteristics of a Cancer Pain Classification System

- Comprehensive
- Prognostic
- Simple to use

Validation Studies

- Fainsinger et al. (2005): A multicenter study of the revised Edmonton Staging System for classifying cancer pain in advanced cancer patients (n=750)
- Nekolaichuk et al. (2005): A validation study of a pain classification system for advanced cancer patients using content experts (n=70)
- Fainsinger et al. (in progress): An international multicentre validation study of a pain classification system for advanced cancer patients

Summary of Reliability & Validity Studies

- moderate to high inter-rater reliability (Fainsinger et al., 2005)
- good predictive value for complexity of care (Fainsinger et al., 2005)
- construct validity evidence using expert panel (Nekolaichuk et al., 2005)
- reproducibility across different settings (Fainsinger et al., in progress)

1) Update on ECS-CP study

Data Received as of May 08

Study Site	No. of teleforms completed
Calgary, AB	100
Edmonton, AB, site 1 RAH	100
Edmonton, AB, site 2 TPCU	100
Houston, TX, site 1 Dr. Zhuckovsky	100
Houston, TX, site 2, Dr. Fisch	100
Auckland, NZ, site 1, Middlemore Hospital	100
Auckland, NZ, site 2, Auckland Hospice	100
Melbourne, Australia	100
Tel Aviv, Israel	100
Dublin	100

Web Site for ECS_CP Study

<http://www.palliative.org/PC/ECS-int/ecs-int.htm>

Edmonton Classification System for Cancer Pain

Multicenter Study

- [Administrative manual](#)
- ECS-CP (powerpoint format) (pdf format)
- [Teleform and data information guide](#)
- Resources
 - [CAGE](#)
 - [ESAS](#)
 - [Karnofsky](#)
 - [MEDD](#)
 - [Pain Assessment/Management Standard](#)
 - [Patient Monitoring Chart](#)
- Downloadable data collection forms



Auckland Hospice, New Zealand	Auckland Middlemore, New Zealand
Dublin, Ireland	Calgary, Canada
Edmonton RAH, Canada	Edmonton TPCU, Canada
Houston, USA	Houston, USA (Dr. Fisch)
Inverness, Scotland	Kelowna, Canada
Melbourne, Australia	Milan, Italy
New York, USA	St. Johns, Canada
Tel Aviv, Israel	Toronto, Canada



Edmonton Folk Festival

<http://www.palliative.org/PC/ECS-int/ecs-int.htm>

Teleform as data collection tool:

- is based on optical recognition technology
- enables user to create data collection forms
- allows distribution by fax, email, web as downloadable or by hand
- receives filled form electronically via fax or scanner
- auto-exports verified data to a database

Clinical Assessment Tools in Predicting Survival of Terminally Ill Patients in Different Palliative Care Settings

Please fax filled forms to 735-7862

Study ID

1 ☐ ☐ ☐ ☐ ☐ ☐

2 ☐ ☐ ☐ ☐ ☐ ☐

3 ☐ ☐ ☐ ☐ ☐ ☐

4 ☐ ☐ ☐ ☐ ☐ ☐

5 ☐ ☐ ☐ ☐ ☐ ☐

6 ☐ ☐ ☐ ☐ ☐ ☐

7 ☐ ☐ ☐ ☐ ☐ ☐

8 ☐ ☐ ☐ ☐ ☐ ☐

9 ☐ ☐ ☐ ☐ ☐ ☐

0 ☐ ☐ ☐ ☐ ☐ ☐

Assessment Date

M M D D Y Y

1 ☐ ☐ ☐ ☐ ☐ ☐

2 ☐ ☐ ☐ ☐ ☐ ☐

3 ☐ ☐ ☐ ☐ ☐ ☐

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Referral Date

M M D D Y Y

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9 ☐ ☐ ☐ ☐ ☐ ☐

0 ☐ ☐ ☐ ☐ ☐ ☐

Discharge/Death Date

M M D D Y Y

1 ☐ ☐ ☐ ☐ ☐ ☐

2 ☐ ☐ ☐ ☐ ☐ ☐

3 ☐ ☐ ☐ ☐ ☐ ☐

4 ☐ ☐ ☐ ☐ ☐ ☐

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Karnofsky Performance Scale (KPS)

☐ 0 ☐ 10 ☐ 20 ☐ 30 ☐ 40 ☐ 50 ☐ 60 ☐ 70 ☐ 80 ☐ 90 ☐ 100

Palliative Performance Scale (PPS)

☐ 0 ☐ 10 ☐ 20 ☐ 30 ☐ 40 ☐ 50 ☐ 60 ☐ 70 ☐ 80 ☐ 90 ☐ 100

Eastern Cooperative Oncology Group (ECOG)

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ Unable to assess

Present Location

☐ Home

☐ Acute Care

☐ Long Term Care

☐ Hospice

Palliative Prognostic Score (PaP)

Dyspnea ☐ No ☐ Yes Anorexia ☐ No ☐ Yes

Karnofsky Performance Status (KPS) ☐ ≥ 30 ☐ ≤ 20

Clinical Prediction of Survival [in weeks] (CPS) ☐ 1-2 ☐ 3-4 ☐ 5-6 ☐ 7-8 ☐ 9-10 ☐ 11-12 ☐ >12

Total WBC ☐ Normal (4.8-8.4) ☐ High (8.5-11) ☐ very High (>11)

Lymphocyte % ☐ Normal (20-40) ☐ Low (12-19.9) ☐ very low (<11.9)

Palliative Prognostic Index (PPI)

Palliative Performance Scale (PPS) ☐ 10-20 ☐ 30-50 ☐ ≥ 60

Oral Intake ☐ $>$ Severly Reduced ☐ Moderately Reduced ☐ Normal

Edema ☐ Present ☐ Absent

Dyspnea at Rest ☐ Present ☐ Absent

Delirium ☐ Present ☐ Absent

Data Collector

☐ Joan Faily

☐ Ingrid Dekock

☐ Sarah Burton Macleod

☐ Noush Mirhosseini

☐ Cari Richards

☐ Sue Campbell

☐ Consult Nurses

Example with recognizable selection

Mechanism of Pain

☐ No

☒ Nc

☐ Ne

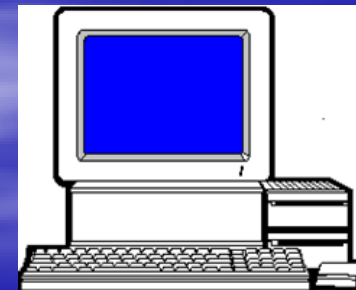
☐ Nx

Teleform as data collection tool:



Teleform generates data entry form

- * Clinician or research staff enter data onto forms
- * Research staff checks data entry forms for data completeness before faxing



Teleform

- * Reads and verifies data
- * Exports data to a database

1991

3 months to complete

- 100 consecutive charts of patients dying on TPCU
- Funding 0\$
- Ethics – none required
- Location – dusty archives
- Research assistant – pregnant wife

2008

8 years +

- Multicentre 750 pts
- Construct 70 experts
- International 10 sites & 1000+ pts
- Funding \$150000
- PhD co-investigator
- Data base manager
- Research manager & research assistants
- Ethics for all sites

Edmonton Palliative Care Research Legacy

1986 - 2008

The University of Alberta Chair in
Palliative Medicine

Neil MacDonald

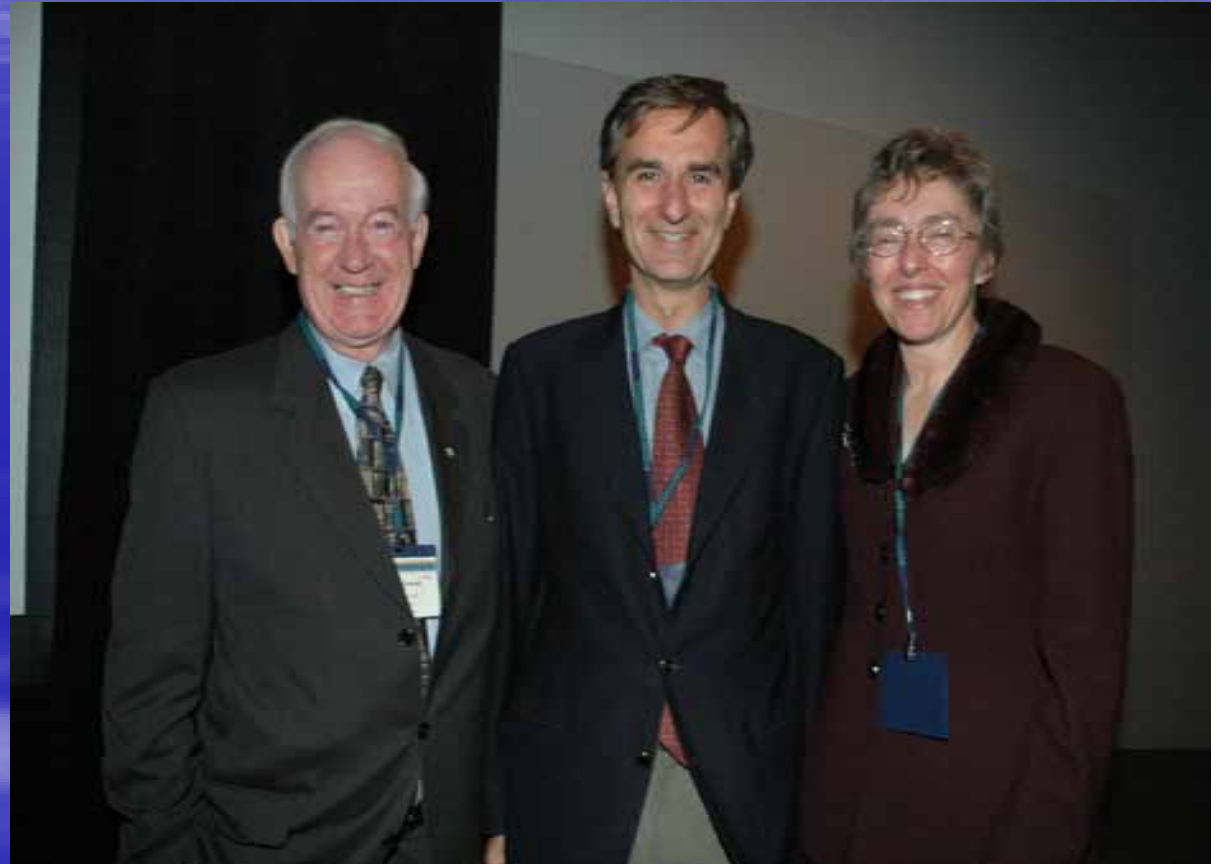
- vision & advocacy

Eduardo Bruera

- ideas, innovation, energy,
research productivity

Vickie Baracos

- Skilled basic scientist &
cachexia research theme
- “there was darkness in the world
& then there was light” – Ken
Fearon



Research in Palliative Care

A research future

Vickie Baracos PhD

Robin Fainsinger, MD

Cheryl Nekolaichuk, PhD

Sharon Watanabe, MD

Konrad Fassbender, PhD

Karin Olson, RN, PhD

Wendy Wismer, PhD

Academic & clinical medical
Faculty

Not many programs will have these
“rare birds” – MacDonald 1992



Research reflections 1991 vs 2008

- Enthusiastic leader & mentor
- 14 patient unit
- No work computer
- No money
- No literature/textbook
- No research staff
- Limited ethics needs
- Simple research efforts productive
- Integrated program
- 3 PhD appointments
- Computers +++++
- Huge database
- Funding for research
- Literature/textbooks
- Ethics for everything
- Core funding
- Research takes more time

National/International Collaboration

- Requires personnel
- Research expertise
- Administrative support
- Adequate funding
- Communication – tele/video conferences, travel, websites
- Time!!!

Benefits vs Challenges of warming of our research environment

- Money for infrastructure!
- Attracts new researchers
- Inter-disciplinary teams
- Encourages collaboration
- Makes your university happy!
- Complex structures
- More time on meetings – talk vs action
- Multi-site leadership & teleconferences
- MIAs – sign on but remain off!
- Need to deliver!

Developing PC Research

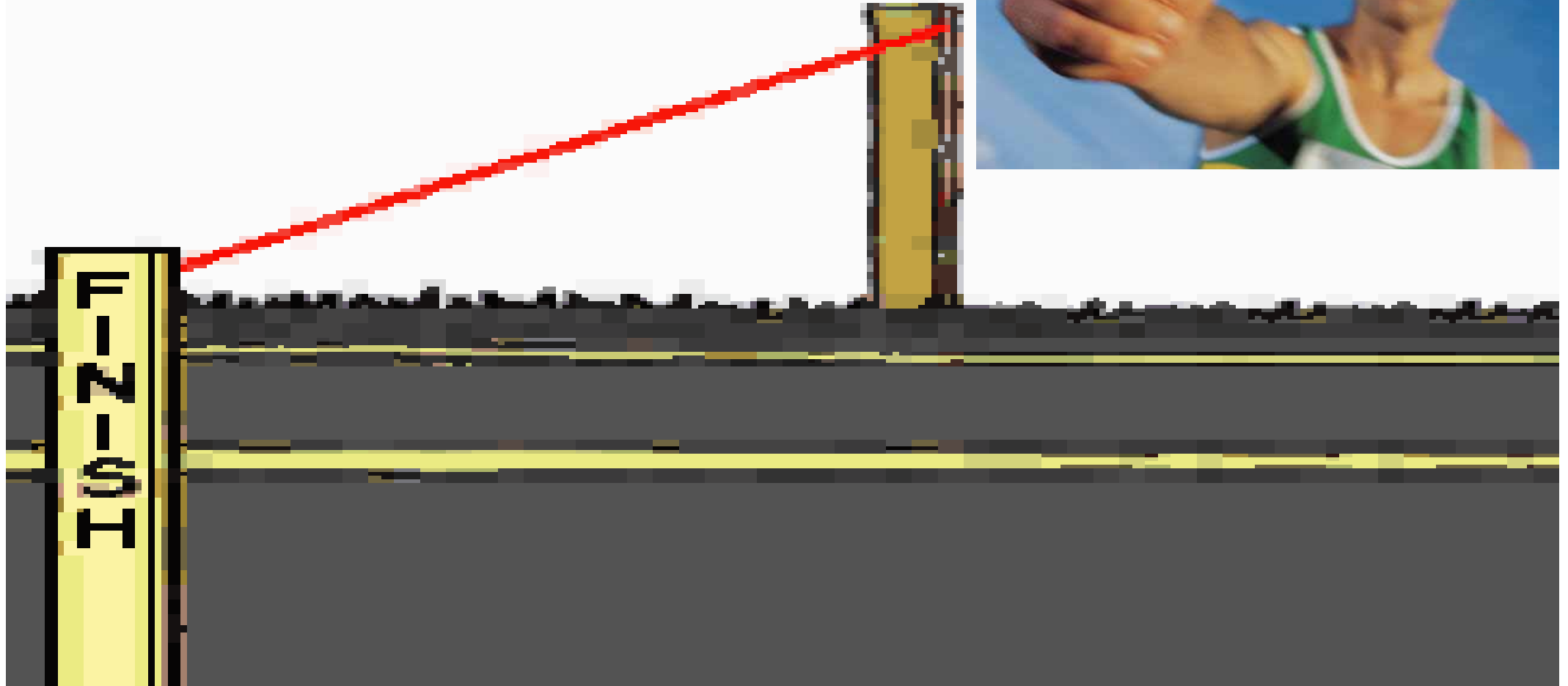
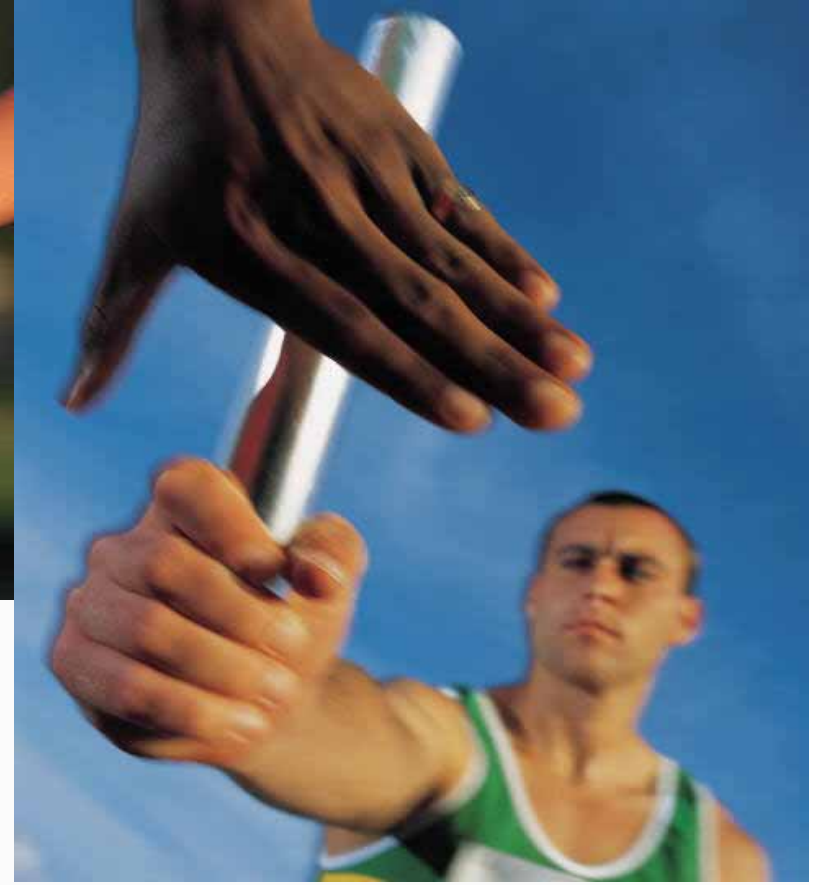
Moving forward

- What are our clinical questions?
- What is our research question?
- What resources do we have &/or need to do the research?
- Can we develop an interdisciplinary research team?
- Can we take advantage of national & international collaborations?

- How can we use research to improve QOL for patients & families & Quality of Care delivered by our clinical programs?
- How do we continue to advocate & maintain funding?
- Good research takes time – this involves a marathon, not a sprint

Is the glass half empty or half full? A common expression, used to indicate a particular situation could be a cause for optimism (half full) or pessimism (half empty)





*Come gather 'round people wherever
you roam
And admit that the waters around you
have grown
And accept it that soon you'll be
drenched to the bone
If your time to you is worth savin'
Then you better start swimmin' or you'll
sink like a stone
For the times they are a changin'
Bob Dylan*