Comprehensive Care for HAE

- All is not swell? -

Leading with Innovation
Serving with Compassion
ST. MICHAEL'S HOSPITAL
A teaching hospital affiliated with the University of Toronto

UNIVERSITY OF TORONTO

Objectives

1) Review current recommendations for comprehensive care for HAE in Canada
2) Show what we have achieved and what still needs work.
3) Propose and discuss strategies to accomplish unmet needs.


EAT
MOR
CHIKIN

Declaration of Funding

Advisory Boards and Consultancy

- Canadian Blood Services, CSL Behring, Shire, Talecris, Viropharma

Speaker's Honoraria

- Shire, CSL, Octapharma

Research Funding

- CSL Behring, Pharming, Talecris, Green Cross, Octapharma


TWO HATS

CHAEN

- **Vision:**

Enable HAE patients in Canada to receive appropriate support and care so that they are able to live full lives

- **Mission:**

CHAEN unites physicians committed to ensuring all HAE patients in Canada have access to excellent care that reflects current management and treatment guidelines, and works to promote research and education

Betschel *et al. Allergy, Asthma & Clinical Immunology* 2014, **10**:50
http://www.aacijournal.com/content/10/1/50

ALLERGY, ASTHMA & CLINICAL IMMUNOLOGY

POSITION ARTICLE AND GUIDELINES Open Access

Canadian hereditary angioedema guideline

Stephen Betschel[1*], Jacquie Badiou[2], Karen Binkley[1], Jacques Hébert[3], Amin Kanani[4], Paul Keith[5], Gina Lacuesta[6], Bill Yang[7], Emel Aygören-Pürsün[8], Jonathan Bernstein[9], Konrad Bork[10], Teresa Caballero[11], Marco Cicardi[12], Timothy Craig[13], Henriette Farkas[14], Hilary Longhurst[15], Bruce Zuraw[16], Henrik Boysen[17], Rozita Borici-Mazi[18], Tom Bowen[19], Karen Dallas[20], John Dean[21], Kelly Lang-Robertson[1], Benoît Laramée[22], Eric Leith[23], Sean Mace[1], Christine McCusker[24], Bill Moote[25], Man-Chiu Poon[26], Bruce Ritchie[27], Donald Stark[4], Gordon Sussman[1] and Susan Waserman[5]

Treatment of HAE

- Acute Attacks
- Prophylaxis
  - Short-term
  - Long-term
- Self-Administration
- Approach to Individualized Therapy
- Quality of Life
- Comprehensive Care

Rapid publication

Canadian 2003 International Consensus Algorithm for the Diagnosis, Therapy, and Management of Hereditary Angioedema

Tom Bowen, MD, FRCPC,* Marco Cicardi, MD (on behalf of PREHAEAT),†*
Henriette Farkas, MD PhD,* Konrad Bork, MD,‡ Wolfhart Kreur, MD,*

C1 inhibitor deficiency: consensus document

Hereditary angiodema: a current state-of-the-art review, VII: Canadian Hungarian 2007 International Consensus Algorithm for the Diagnosis, Therapy, and Management of Hereditary Angioedema

Tom Bowen, MD, FRCPC; Marco Cicardi, MD; Konrad Bork, MD; Bruce Zuraw, MD; Mike Frank, MD;

REVIEWS

Consensus Statement on the Diagnosis, Management, and Treatment of Angioedema Mediated by Bradykinin. Part I. Classification, Epidemiology,

ment on the Diagnosis, d Treatment of Angioedema dykinin. Part II. Treatment, pecial Situations

kinin-Induced Angioedema (SGBA) (Grupo Español liado por Bradicinina: GEAB)

Cabañas,[1#] A Campos,[4#] S Cimbollek,[5#]

Hereditary angioedema with normal C1 inhibitor function: Consensus of an international expert panel

Bruce L. Zuraw, M.D.,[1,2] Konrad Bork, M.D.,[3] Karen E. Binkley,
Sandra C. Christiansen, M.D.,[1,6] Anthony Castaldo, M.P.A.,[7] Al
Charles Kirkpatrick, M.D.,[10] Markus Magerl, M.D.,[11] Christian l
and Marco Cicardi, M.D.[13]

ABSTRACT

A new form of hereditary angioedema (HAE) with normal C1 inhibitor (C1I
diagnostic criteria, the heterogeneity among affected patients, and the var
substantial confusion among both physicians and patients. This study was des
An international symposiun
cians who evaluate and manag
ients with recurrent angioed
scussed. The co
with HAE wit
llergy Asthma

Bowen et al. Allergy, Asthma & Clinical Immunology 2010, 6:24
http://www.aacijournal.com/content/6/1/24

ALLERGY, ASTHMA & CLINICAL IMMUNOLOGY

REVIEW Open Access

2010 International consensus algorithm for the diagnosis, therapy and management of hereditary angioedema

Tom Bowen[1*], Marco Cicardi[2], Henriette Farkas[3], Konrad Bork[4], Hilary J Longhurst[5], Bruce Zuraw[6],
Emel Aygoeren-Pürsün[7], Timothy Craig[8], Karen Binkley[9], Jacques Hebert[10], Bruce Ritchie[11], Laurence Bouillet[12],

Betschel et al. Allergy, Asthma & Clinical Immunology 2014, 10:50
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ALLERGY, ASTHMA & CLINICAL IMMUNOLOGY

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Practice paper

International consensus and practical guidelines on the gynecologic and obstetric management of female patients with hereditary angioedema caused by C1 inhibitor deficiency

Teresa Caballero, MD, PhD, Henriette Farkas, MD, PhD, DSc,[b]* Laurence Bouillet, MD, PhD,[c]* Tom Bowen, MD,[d] Anne Gompel, MD, PhD,[e] Christina Fagerberg, MD,[f] Janne Björkander, MD,[g‡§] Konrad Bork, MD,[h‡§]**

Allergy EUROPEAN JOURNAL OF ALLERGY AND CLINICAL IMMUNOLOGY EAACI

Allergy

POSITION PAPER

Classification, diagnosis, and approach to treatment for angioedema: consensus report from the Hereditary Angioedema International Working Group

M. Cicardi[1], W. Aberer[2], A. Banerji[3], M. Bas[4], J. A. Bernstein[5], K. Bork[6], T. Caballero[7], H. Farkas[8], A. Grumach[9], A. P. Kaplan[10], M. A. Riedl[11], M. Triggiani[12], A. Zanichelli[1] & B. Zuraw[11] on behalf of HAWK, under the patronage of EAACI (European Academy of Allergy and Clinical Immunology)*

[1]Luigi Sacco Hospital Milan, Milan, Italy; [2]Department of [3]Allergy and Immunology, Massachusetts General [4]Technische Universität München, Munich, [5]University of Cincinnati College of Medicine, [6]Mainz, Germany; [7]Department of Allergy, Hospital La [8]Diseases–U754 (CIBERER), Madrid, Spain; [9]3rd [10]Budapest, Hungary; [11]Department of Clinical [12]South Carolina, Charleston, SC; [13]Division of Rheumatology, [14]Diego, La Jolla, CA, USA; [15]Department of Medicine,

Caballero T, Farkas H, Grumach A, Kaplan AP, Riedl MA, Triggiani M, [16]demy of Allergy and Clinical Immunology). Classification, diagnosis, and [17]International Working Group. Allergy 2014; DOI: 10.1111/all.12380.

Allergy EUROPEAN JOURNAL OF ALLERGY AND CLINICAL IMMUNOLOGY EAACI

Allergy

REVIEW ARTICLE

Evidence-based recommendations for the therapeutic management of angioedema owing to hereditary C1 inhibitor deficiency: consensus report of an International Working Group

M. Cicardi[1], K. Bork[2], T. Caballero[3], T. Craig[4], H. H. Li[5], H. Longhurst[6], A. Reshef[7] & B. Zuraw[8] on behalf of HAWK* (Hereditary Angioedema International Working Group)

[1]Dipartimento di Scienze Cliniche "Luigi Sacco", Università di Milano, Ospedale L. Sacco, Milano, Italy; [2]Department of Dermatology, Johannes Gutenberg University, Mainz, Germany; [3]Servicio de Alergia, Hospital Universitario La Paz, Health Research Institute, IdiPaz, Madrid, Spain; [4]Departments of Medicine and Pediatrics, Penn State University, Hershey, PA; [5]Institute for Asthma and Allergy, Wheaton, MD, USA; [6]Barts and the London NHS Trust, London, UK; [7]Sheba Medical Center, Tel Aviv University, Tel Aviv, Israel; [8]University of California, San Diego, CA, USA

WAO GUIDELINE

WAO Guideline for the Management of Hereditary Angioedema

Timothy Craig, DO,[1] Emel Aygören Pürsün, MD,[2] Konrad Bork, MD,[3] Tom Bowen, MD,[4] Henrik Boysen,[5] Henriette Farkas, MD PhD,[6] Anete Grumach, MD PhD,[7] Constance H. Katelaris, MB BS PhD,[8] Richard Lockey, MD,[9] Hilary Longhurst, MD,[10] William Lumry, MD,[11] Markus Magerl, MD,[12] Immaculada Martinez-Saguer, MD PhD,[2] Bruce Ritchie, MD,[13] Alexander Nast, MD,[12] Ruby Pawankar, MD PhD,[14] Bruce Zuraw, MD,[15] and Marcus Maurer, MD[12]

Comprehending Comprehensive Care

Comprehensive care of patients is based on integration of the organization, delivery, and management of services related to diagnosis, treatment, care, rehabilitation and health promotion.

Recommendation	Level of Evidence	Strength of recommendation
Comprehensive care should be available for all patients with HAE	Low	Strong

Although the importance of the comprehensive care model in HAE was recognized by the committee unanimously, and specific recommendations have existed with respect to its requirements, this care model is not available to all patients with HAE in Canada.

The provincial and territorial model of health care funding makes implementation of nationally uniform HAE comprehensive care clinics challenging.

Despite this, the fundamentals of comprehensive care should be uniform across the country and equally accessible across all geographic locations.

Support should be provided by provincial and territorial governments to ensure that proper standards of care are being met.

Treatments for HAE can be expensive; however inappropriate treatment of HAE may be even more costly.

It was recognised by the committee that on-going monitoring of comprehensive care programs is essential to measure their impact on patients' outcomes such as disease control, QoL and economic effects.

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Table 4 Requirements for comprehensive care in the management of hereditary angioedema patients

Best Clinical Treatment outcomes including:

a. A comprehensive care team made up of nurse coordinator, clinician, social worker, data manager, pain management specialist, genetic counsellor, and administrative support;

b. Access to specialized diagnostic testing;

c. Access to home treatment;

d. A networked Patient Information System to facilitate product recalls - collect data on therapy outcome measures and safety, and facilitate participation in clinical trials

e. Access to clinical advances as they become available;

f. Access to 24 hour support;

g. Access to up-to-date standards of care, including standardized wallet cards;

h. Tracking and intermittent audit of quality outcomes including beneficial and adverse outcomes through secure, comprehensive and networked data management.

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Our Clinic at St Michael's

- Quaternary Centre with a number of specialties available
- Acts as a training centre for pediatric and adult specialties
- Has a dedicated clinic space
- Nurses are focused but not exclusive
- Outstanding blood bank

Dedicated Sources of Support


NOTHING

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CHAEN 2014 Laboratory Survey of Members

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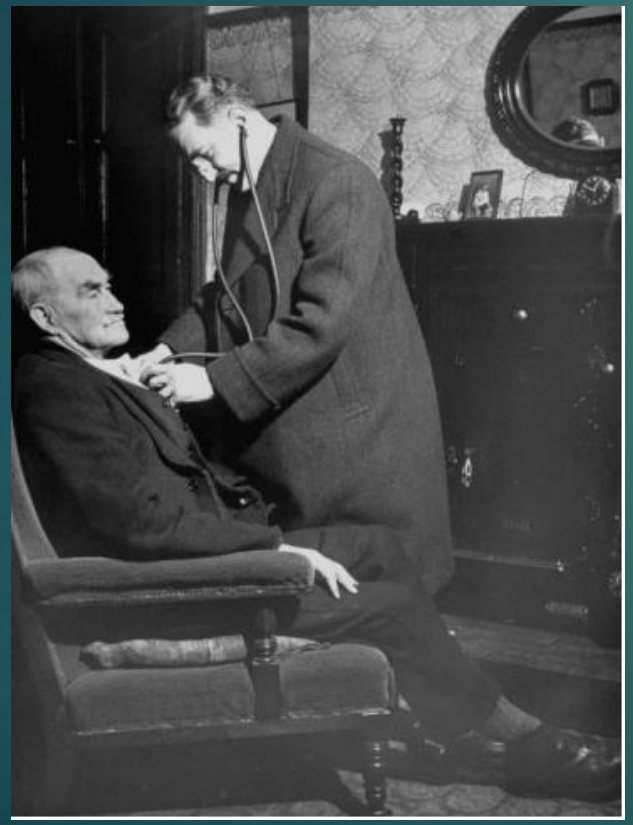
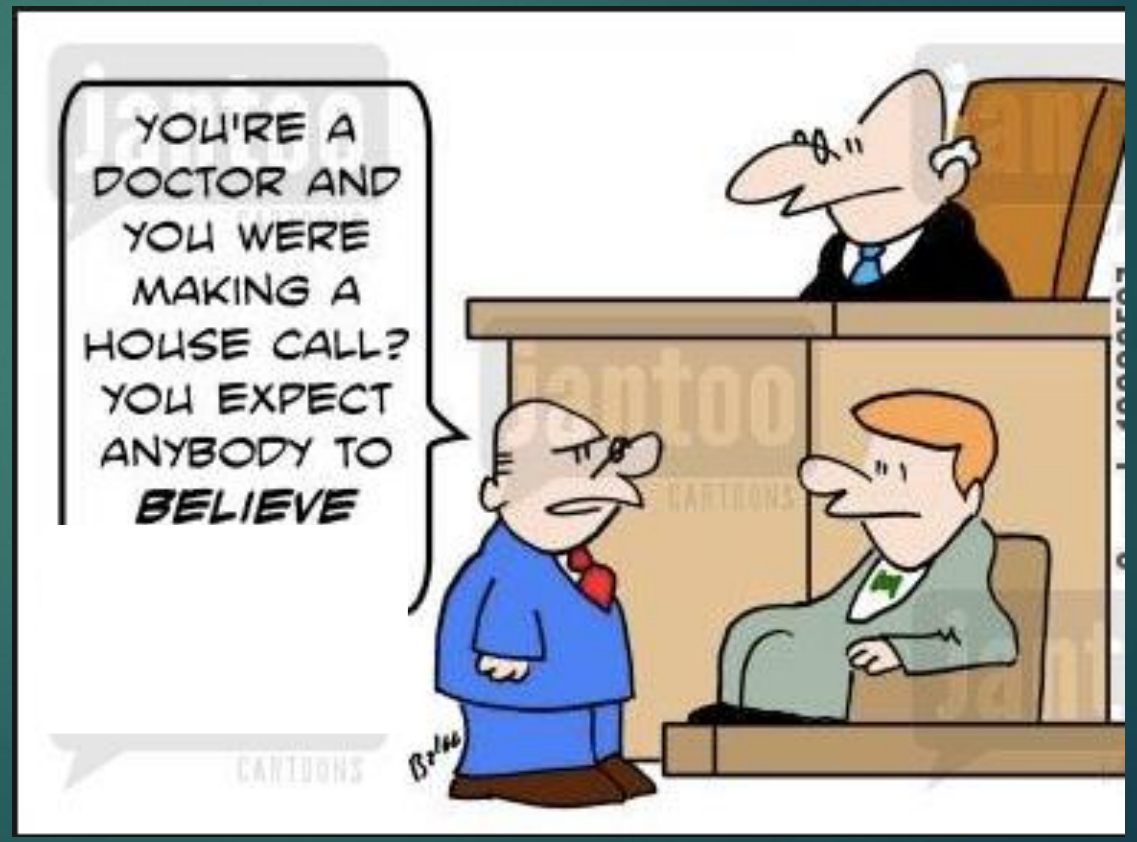
Home Treatment

Then and Now?





2014 Mandate letter: Health and Long-Term Care

Premier's instructions to the Minister on priorities for the year 2014

Putting Patients at the Centre — the Right Care, Right Place, Right Time

- "Continuing to expand home and community care to ensure that people receive care as close to home as possible."

Gerth *et al. Allergy, Asthma & Clinical Immunology* 2014, **10**:23
http://www.aacijournal.com/content/10/1/23

ALLERGY, ASTHMA & CLINICAL IMMUNOLOGY

SHORT REPORT **Open Access**

Implications to payers of switch from hospital-based intravenous immunoglobulin to home-based subcutaneous immunoglobulin therapy in patients with primary and secondary immunodeficiencies in Canada

William C Gerth[1*], Stephen D Betschel[2] and Arthur S Zbrozek[3]

Home-Based Subcutaneous Immunoglobulin Therapy vs Hospital-Based Intravenous Immunoglobulin Therapy: A Prospective Economic Analysis Annals of Allergy, Asthma & Immunology; Fu et al. Annals of Allergy, Asthma and Immunology, (in Press)

Health Quality Ontario

Let's make our health system healthier

Home-Based Subcutaneous Infusion of Immunoglobulin for Primary and Secondary Immunodeficiencies: OHTAC Recommendation

ONTARIO HEALTH TECHNOLOGY ADVISORY COMMITTEE RECOMMENDATION

- OHTAC recommends that home-based subcutaneous infusion of immunoglobulin be publicly funded for treatment of patients with primary and secondary immunodeficiencies

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24/7


EMERGENCY
AMBULANCE ENTRANCE
WEST COAST - SOUTHERN
AMBULANCE
EMS
EMS
AMBULANCE
123

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Registry

- Should be disease specific
- Collect metrics on HAE (diagnostics, genetics, attack specifics and triggers, treatments, response to treatments, QoL)
- Collect data that enables calculation of socioeconomic impact of HAE
- Track product utilization for measures of efficacy, safety, and accountability.

Summary

- Comprehensive care is not new and not unique to rare diseases.
- Lack of standardization between rare blood disorders despite common themes.
- Treatments continue to evolve and move from regimented hospital based therapies to home-based therapies.
- Recognition of this is expanding and is being embraced.
- Despite this, there is no coordinated effort to track appropriate utilization of products and their efficacy.
- Comprehensive care clinics could manage this with appropriate support that would likely be cost effective.

Bridging the Gap

Bridging the Gap

Recommended

Bridging the Gap

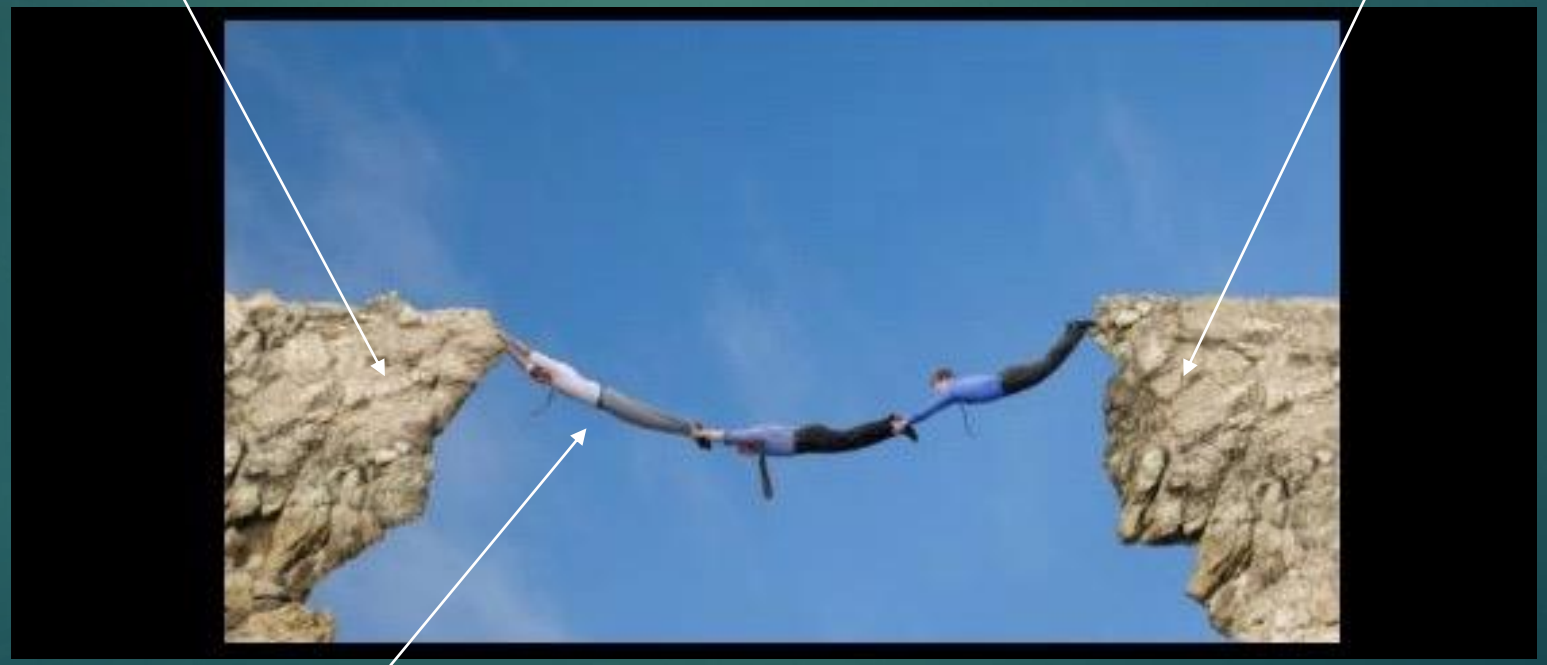
Recommended

Reality

Bridging the Gap

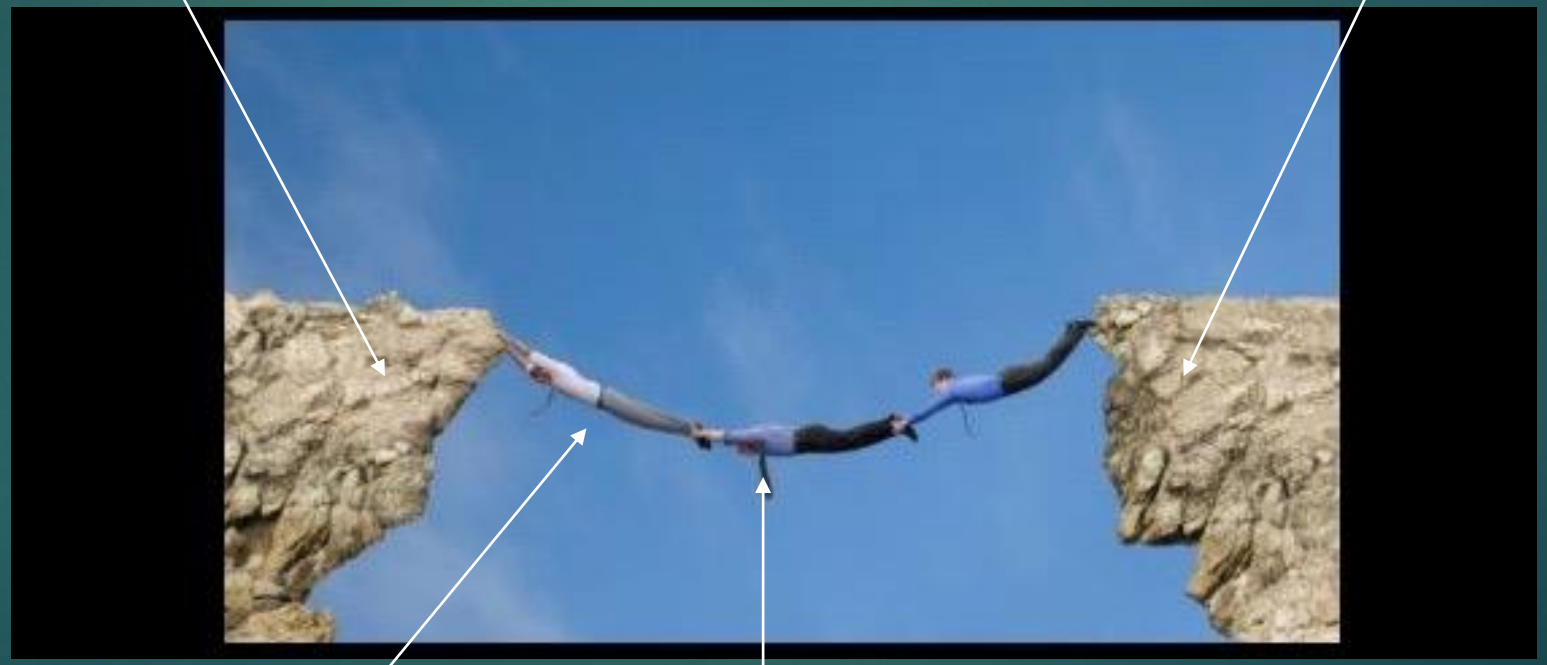
Recommended

Reality



Health care providers

Bridging the Gap



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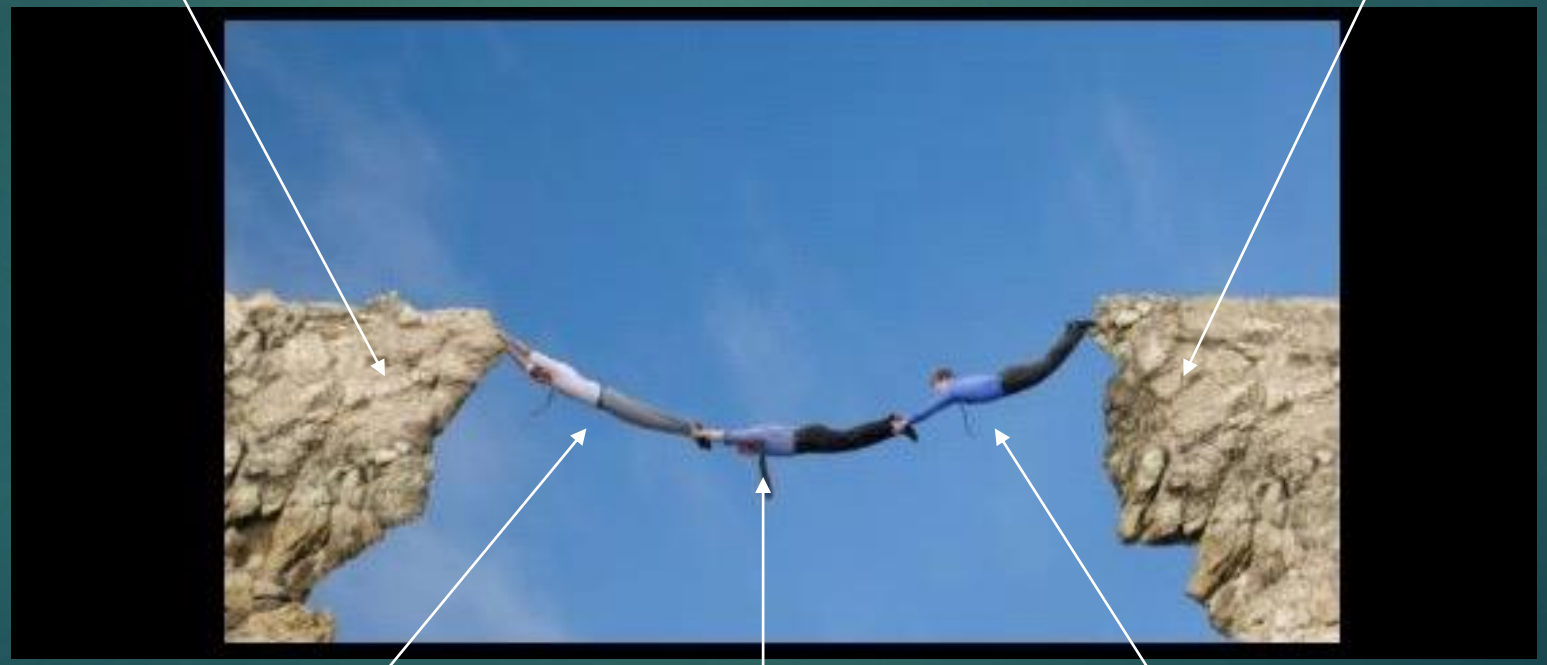

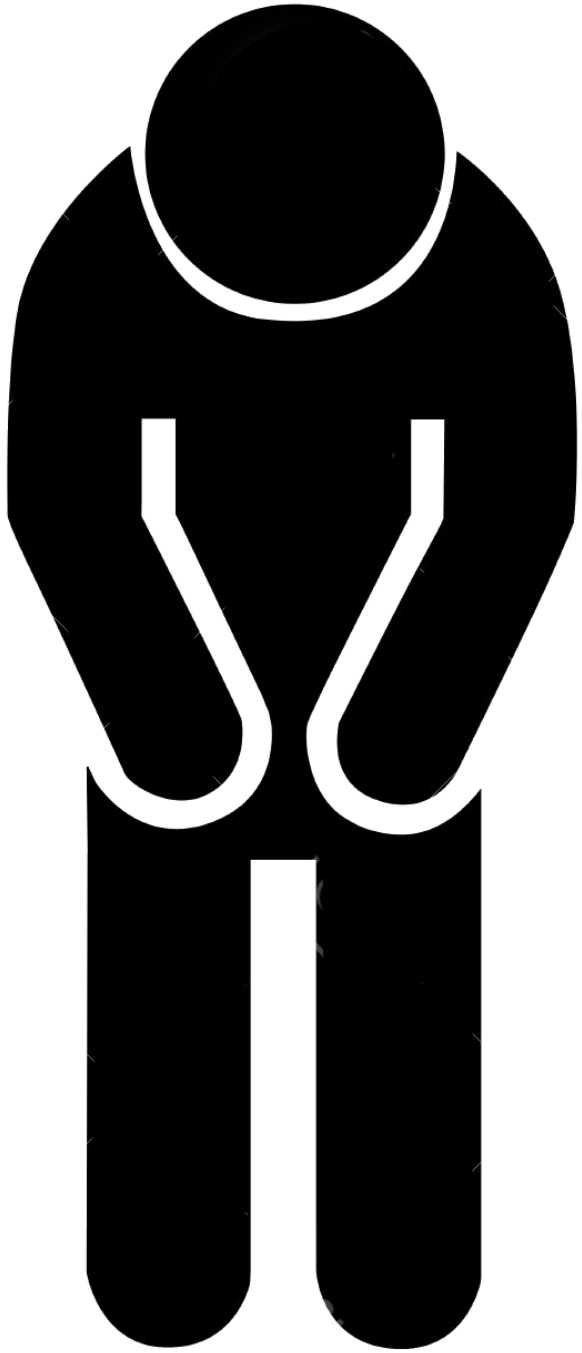

Thank you!