The Canadian Consortium for Neurodegeneration in Aging: Taking Research to the community

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CCNA – Bringing Together Canadian Expertise

Consortium of expert teams

340 Canadian scientists covering all aspects of dementia research
CCNA Initiative – The Canadian Consortium for Neurodegeneration and Aging

Theme: Primary Prevention
- Team-Inflammation
- Team-Synapses
- Team-Prevention
- Team-Genetics

Theme: Secondary Prevention
- Team-Driver
- Team-Cognitive Training
- Team-Health Systems
- Team-Mobility
- Team-Caregivers

Integrated themes:
- Capacity building / KT/ Ethics
- Ethics

Eight supporting platforms
CCNA – our objectives

1. To transform the Canadian NDD community into a synergistic clinical and research network.

2. To create a novel Canadian dementia research infrastructure that will transform Canada into a single Alzheimer’s Disease Research Centre (ADRC).
   • clinical assessments • imaging protocols • biobanking protocols • brain banking • biomarkers: all are coordinated, shared and made available for the broadest use.

3. To address issues that are of particular importance within the Canadian landscape, including service delivery challenges, care for indigenous individuals, and addressing challenges of care within different provincial systems.

4. To include Teams focussing on neurodegenerative diseases beyond Alzheimer’s disease: LBD, VCI, FTD, PDD –
   • common mechanisms • comorbidities • distinctive and shared pathologies

5. To position this Canadian network to partner globally and to move quickly.

6. Provide a mechanism to link researchers with the community and patients and their families.
CCNA

CIHR Total
21.65 Million

Partners Total
11.855 Million

Including the Alzheimer Society Of Canada

Five Year Budget
$33.505 Million

Cross-Cutting Programs
[Total = $2,015,000]
1. Training $387,500
2. KT- $977,500
3. Ethics-$350,000
4. Women and Gender-$300,000

Platforms
[Total = $9,331,865]
1. $3,187,500
2. $290,000
3. $2,486,365
4. $1,184,000
5. $484,000
6. $900,000
7. $500,000
8. $300,000

Administrative Costs
$1,740,625

TEAM COSTS

Theme 1
$6,040,000

Theme 2
$7,341,410

Theme 3
$7,189,893

Including the Alzheimer Society Of Canada
Canadian Issues:
• Rural service delivery
• Provincial health care systems
• Use of single payer system
• Cohesion across disciplines
• Collaborative structure

International issues:
• NDD as global problems
• Vascular emphasis
• Gender emphasis
• Excellence of researchers
• Need for novel molecules, new approaches, three themes
Cohorts of patients with different dementias - Alzheimer’s, Frontotemporal, Lewy Body, Vascular

National centres for Biomarkers and brain bank specimens - blood, cerebrospinal fluid, brain sample donation.

- Accepting specimens from across the country
- Coordinated national genetics, brain imaging, psychology testing – all in a shared database

Coordination between Canadian researchers and greater synergy

Collaboration with international groups.
Teams- Theme 1
Prevention of cognitive impairment and dementia

Jane Rylett, David Hogan

Team 1 - Clinical genetics and gene discovery
Peter St. George-Hyslop (U.of T.) [Guy Rouleau presenting]

Team 2 - Inflammation and Nerve Growth Factors
Claudio Cuello (McGill)

Team 3 - Protein Misfolding
Neil Cashman (UBC)

Team 4 - Synapses and metabolomics
Robert Bartha (Western)

Team 5 - Lipid and Lipoprotein Metabolism
Cheryl Wellington (UBC)

Team 6 - Nutrition, Exercise and Lifestyle in AD prevention
Carol Greenwood (U. of T.)
Teams- Theme 2
Treatments
Sandra Black, Mario Masellis

Team 7 - Vascular illness and its impact on NDD
Eric Smith (Calgary)

Team 8 - Lewy Bodies (PDD and LBD), Aging, and Dementia
Richard Camicioli (Alberta) [Mario Masellis presenting]

Team 9 - Developing New Biomarkers
Roger Dixon (Alberta)
Pierre Bellec (U. de Montréal)

Team 10 - Cognitive Intervention and Brain Plasticity
Sylvie Belleville (U. de Montréal)

Team 11 - Prevention and Treatment of Neuropsychiatric Symptoms
Nathan Herrmann (U. of T.) [Sandy Black presenting]

Team 12 - Mobility, Exercise and Cognition
Manuel Montero-Odasso (Western) [Sandy Black presenting]

Team 13 - Frontotemporal dementia
Robin Hsiung (UBC)
Teams- Theme 3
Quality of Life
Ken Rockwood

Team 14 - How multi-morbidity modifies the risk of dementia and the patterns of disease expression
Melissa Andrew (Dalhousie)

Team 15 - Gerontechnology and dementia
Alex Mihailidis (U. of T.) [Ken Rockwood presenting]

Team 16 - Driving and dementia
Gary Naglie (U. of T.)

Team 17 - Interventions at the Sensory and Cognitive Interface
Natalie Phillips (Concordia)

Team 18 - Program to improve the effectiveness of dementia caregivers
Joel Sadavoy (U. of T.)

Team 19 - Integrating dementia patient care into the health care system
Howard Bergman (McGill)

Team 20 - Issues in dementia care for rural and indigenous populations
Debra Morgan (U. Saskatchewan)
Kristen Jacklin (U. Northern Ontario).
Platforms: Clinical, Biomarkers, Imaging, Neuropsychology, Genetics, Brain Banks

Key - Arrows
Red – one-way interaction within theme
Blue – two-way interaction within theme
Pink – one-way interaction across themes
Green – two-way interaction across themes

1. Genetics
2. Inflammation
3. Protein Misfold
4. Synapse
5. Lipoprotein
6. Exercise, Lifestyle
7. Vascular
8. Parkinson's
9. Biomarkers
10. Cognitive Therapy
11. Neuropsychiatric
12. Mobility
13. FTD
14. Comorbidity
15. Gerontechnology
16. Driving
17. Sensory Interface
18. Caregivers
19. Health Care System
20. Rural, Indigenous

ELSI

Women

Theme 1
Theme 2
Theme 3
An important emphasis of the CCNA: Making certain that new research knowledge will be used by the community.

There are many terms for KT and many definitions, but they all have a common theme:
“…a move beyond the simple dissemination of knowledge into the actual use of knowledge”.

(Straus 2009).
The CDKTN is a government-funded Canadian national network for knowledge translation (KT) and Knowledge Exchange (KE) for research in dementia established in 2009. It will now become the KT arm of the CCNA.
Focuses on

• development of training programs and opportunities for researchers and health practitioners in knowledge translation and exchange (KT&E)

• funding opportunities and research projects for the study of KT in dementia research.
SOME EXAMPLES

The Dementia KT Learning Resource Centre – online dementia KT modules for researchers
http://dementiakt.ca/

“A Landscape for Training in Dementia Knowledge Translation (DKT)” Iles, Chahl & Beattie, 2011

– Web based survey of dementia researchers in Canada to assess needs and priorities of DKT for researchers

Webinars:

– From the Lab to the Mainstream: Strategies for Communicating Dementia Research & Care to the Media
Focuses on
• national exchange of dementia resources and knowledge
Creating new ways to know and do.

The Canadian Dementia Resource and Knowledge Exchange (CDRAKE) is a network of people dedicated to improving the quality of life for persons with dementia and their family. Focusing on the national sharing of dementia resources and knowledge through in-person and virtual exchange to support relationships among industry, researchers, clinicians, policy makers, persons with dementia, and care partners, CDRAKE brings together the best and brightest in dementia care to:

- Support the learning needs of people seeking practice change
- Facilitate quick and easy access to the best knowledge for continuous quality improvement
- Stimulate, support and share innovations
- Build and strengthen collaborative partnerships between stakeholders
- Foster direct links between knowledge users and producers

Join the CDRAKE community to be:

- Connected to upcoming online or in-person opportunities by knowledge exchange, innovations in dementia care and links to stakeholders
- Invited to join topic-specific national Communities of Practice (CoPs) where you can connect with people who share a common passion
- Offered ways to showcase your leadership and advancements

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CDRAKE offers:

KT&E Webinars – for example:
- Ways to maximize success when communicating with someone with dementia.
- Palliative approaches to dementia care.
- Vascular dementia.

Access to Communities of Practice
Knowledge Broker Q&A
Focuses on

- providing persons with dementia and care partners with knowledge
- empowering them to use it
Some examples:

Not If But When
- Dementia and driving cessation resource site ([www.nibw.ca](http://www.nibw.ca))

The Palliative and Therapeutic Harmonization (PATH) Clinic
- helpings older people and their families understand their health status and the process of making health care decisions ([www.pathclinic.ca](http://www.pathclinic.ca))

Think Tanks and synthesis to understand research priorities and perspectives of those working in dementia care.
New Knowledge Translation Guides

The CDKTN has produced two new resources for people who want to learn more about Knowledge Translation (KT), an Introduction to KT (PDF) and a KT Planning Guide. You can find them both on our Resources page in the KT Resources Section.

Looking for the 2012 Dementia Diagnosis and Treatment CME?

This CME, designed for primary care physicians, should be available very soon. If you would like to be notified by email when it is online go to our contact page and send a brief message to us. We'll email you directly as soon as the online CME is available. The CDKTN does not share, sell or otherwise forward your email to others.

CDKTN announces a new Dementia KT Training site for researchers

Welcome to Life and Minds - your resource for the latest in dementia related news, events and research.

This website is intended as a resource for news, information and events concerning dementia and dementia research. It is part of a larger project called the Canadian Dementia Knowledge Translation Network (CDKTN), which promotes the translation of dementia research into products, services and information for persons with dementia and their families, as well as caregivers, health professionals, researchers and more. Please visit our About Us page to learn more about this project and the people involved.
Conclusions

• CDKTN will become the KT heart of the new CCNA.
• CCNA is a unique national initiative that not only brings an entire dementia research community together, but puts KT and communication with the community front and centre.
• Future research initiatives internationally should follow this example – KT and community communication is crucial to our success.