Present were: Chair S. Strickland, L. Armstrong, J. Brewer, T. Cowan, D. Craig, R. Deutschmann*, J. Haalboom, B. Halloran*, R. Kelterborn, J. Mitchell, C. Millar*, K. Seiling, J. Wideman and C. Zehr*

Members absent: T. Galloway and G. Lorentz

DECLARATIONS OF PECUNIARY INTEREST UNDER THE MUNICIPAL CONFLICT OF INTEREST ACT

None declared

DELEGATIONS

a) Memo: Revised Motion on Lyme Disease

i) Christine Heffer, Corunna, Ont. addressed the Committee regarding the symptoms and impact of late-stage Lyme disease; a copy of her presentation is appended to the original minutes. Also appended is a copy of her verbal delegation to the Committee.

* R. Deutschmann joined the meeting at 9:08 a.m.
* B. Halloran joined the meeting at 9:10 a.m.
* C. Millar joined the meeting at 9:13 a.m.

C. Heffer highlighted her personal medical experiences and the difficulties in seeking effective and timely medical attention. She also shared with the Committee the challenges she and others face both emotionally and economically. She urged Regional Council and all levels of government to support early and effective treatment, as well as to continue public awareness campaigns and tick dragging efforts.

* C. Zehr joined the meeting at 9:48 a.m.

ii) Wendy Woodhall, Waterloo Region Lyme Disease Group, spoke to the Committee about her personal experiences with Lyme disease; a copy of her verbal presentation is appended to the original minutes. She distributed various informational items regarding Lyme disease. She outlined her medical history and that of her two children, who contracted Lyme disease from her. She expressed her concerns with the testing currently used, the access to expert medical care in Ontario and nation-wide, as well as the general lack of attention and awareness for this disease.

In response to Committee questions about her suggestions for Regional action and her advocacy efforts, W. Woodhall advised that she wants Public Health to establish a database to track Lyme disease incidents and to improve the current tick dragging program. She advised that she hasn’t approached local medical associations for their support since the legislation and
mandate comes from the provincial level of government; the local group has, however, approached the provincial ministry.

Dr. Liana Nolan, Commissioner/Medical Officer of Health, summarized the revisions made to the original motion.

J. Haalboom requested that the motion be amended to include distribution of the memo and the attached report to local Members of Provincial Parliament, Members of Parliament and the provincial Minister of Health. The Committee discussed options for a response to a recent news editorial and J. Brewer agreed that she would prepare a personal response.

Dave Young, Director, Health Protection & Investigation, responded to a Committee inquiry about the outcome and future activities related to tick dragging, by indicating that no ticks were found during the most recent efforts and that additional drags will occur in the fall when the weather is dry and cool. He advised that any findings would be relayed to the Committee through a staff report. Chair Strickland reminded the Committee that Public Health prepares an annual report on infectious diseases and that any developments related to Lyme disease would be noted in that annual report.

In response to Committee comments about enhanced tick dragging Dr. Nolan stated that surveillance is key to Public Health activities and staff will continue to monitor for ticks in the Region.

MOVED by J. Haalboom
SECONDED by J. Brewer

THAT the Regional Municipality of Waterloo request that the Office of the Chief Medical Officer of Health of Ontario continue to stay abreast of the evolving science related to Lyme disease, with particular emphasis on the most effective, validated laboratory testing methods and treatment, as well as continue providing Public Health Units with the latest evidence-based information and guidance to continuously improve provincial and local Lyme Disease Programs, pursuant to information previously presented in Report PH-11-038, dated August 16, 2011;

AND THAT a copy of Report PH-11-038 together with this revised recommendation be sent to the Chief Medical Officer of Health of Ontario, the Minister of Health, local MPs and MPPs.

CARRIED, as amended

PRESENTATIONS

a) Fanis Juma Radstake, African Community Wellness Initiative Re: Diggable Communities Collaborative,

Carol Popovic, Public Health Nurse, introduced Ms. Radstake, a member of Patchwork Community Gardens, and identified the purpose and participants of the Diggable Communities Collaborative. She showed a video clip of a recent television interview with local participants of the program; a link to the video clip is appended to the original minutes. She provided program statistics, highlighted the participant benefits of the program and acknowledged the support of local community partners.

Fanis Juma Radstake shared her personal experiences with the community garden, including the benefits she and other newcomers have gained, as well as the social-economic benefits to the community as a whole.
PH-11-044, Diggable Communities Collaborative

Received for information

REPORTS – Public Health

a) PH-11-039, MTE GlobalTox Agreement

In response to a Committee question about the viability of Lyme disease being reviewed under this agreement, Dr. Nolan clarified the scope of the program but acknowledged that there may be an overlap with communicable diseases and that this could be reviewed as it might relate to environmental changes.

Chair Seiling commented that Dr. Brecher’s area of expertise is with chemical toxins and he summarized the assistance Dr. Brecher provided to Regional staff in the past.

MOVED by J. Wideman
SECONDED by T. Cowan

THAT the Regional Municipality of Waterloo enter into an agreement with MTE GlobalTox, led by Dr. Ron Brecher, for a one year period commencing January 1, 2012, with an option of annual renewal for a maximum of two additional years with a maximum total expenditure over three years of up to $300,000 including all applicable taxes, to be funded within the approved cost shared base budget for Public Health which is cost shared 75/25 with Province of Ontario;

AND THAT the Medical Officer of Health be authorized to enter into such agreements with MTE GlobalTox as may be required to facilitate the implementation of the recommendations in Report PH-11-039, September 27, 2011, with such agreements to be to the satisfaction of the Regional Solicitor.

CARRIED

b) PH-11-040, Public Health Breastfeeding Support Activities and Future Plans Toward Achievement of Baby Friendly Accreditation

Andrea Reist, Director, Child & Family Health, made brief comments and responded to Committee questions regarding the continuous training of health care professionals and the dissemination of supportive information to new nursing mothers.

Received for information

c) PH-11-041, 2011 Public Health Budget Approval & Accountability Agreement

Dr. Nolan advised that this is the first agreement of its kind and that it covers a three-year period. The agreement sets out obligations and updates and replaces previous agreements. She summarized the intent of the agreement and the program areas where new 100% provincial base funding will be focused. She also highlighted the three areas where low-level risks are involved in the new accountability agreement.

Dr. Nolan responded to Committee inquiries about the potential for financial impacts on the Region’s base budgets of provincially mandated programs and she advised the Committee that any financial changes would be shared with Regional Council and would seek review and approval.
MOVED by J. Brewer
SECONDED by B. Halloran

THAT the Regional Municipality of Waterloo enter into the Public Health Accountability Agreement with the Province of Ontario, as attached as Appendix B, effective January 1, 2011 for a term of three years, pursuant to Report PH-11-041;

AND THAT the Regional Municipality of Waterloo increase the 2011 Operating Budget for Public Health by $120,050 gross and $0 net Regional Levy to reflect new 100% provincial base funding for the Enhanced Food Safety – Haines, Enhanced Safe Water, Needle Exchange Program, and Public Awareness; Infection Prevention & Control Week initiatives.

CARRIED

d) PH-11-042, Chief Nursing Officer Initiative

MOVED by K. Seiling
SECONDED by D. Craig

THAT the Regional Municipality of Waterloo approve an increase of 1.0 full time equivalent (FTE) in the Infectious Diseases Dental & Sexual Health Division to support the implementation of the Chief Nursing Officer (CNO) initiative, to be funded 100% by the Ministry of Health & Long Term Care as outlined in Report PH-11-042.

CARRIED

e) PH-11-043, Cost of Nutritious Food Basket in Waterloo Region 2011

Sharlene Sedgwick- Walsh, Director, Healthy Living, Planning & Promotion, responded to the Committee’s expressed concern for families with low incomes having access to nutritious food given the current increase in food costs.

Received for information

f) PH-11-045, Project Health – Supporting Healthy Workplaces in Waterloo Region

Received for information

REPORTS – Social Services


Mike Schuster, Commissioner, Social Services, advised that the report celebrates the 177 people who have transitioned from persistent homelessness; a copy of the complete report is available in the Councillors’ library.

Marie Morrison, Manager, Social Planning, shared a video clip about the program with the Committee; the video is available on the Region’s website. She recognized staff who were involved in the production of the video. She advised that the program has assisted more than 300 people, of which 60% have found and maintained housing, and 20% have transitioned from the intensive support from the program.

The Committee encouraged staff to share the video with the community-at-large wherever possible to ensure that the program continues to enjoy success. The Committee also
congratulated staff and community partners on their efforts to date and offered their continued support of related initiatives.

Received for information

g) SS-11-034, Request for Funding Agreements – Supportive Housing of Waterloo

In response to a Committee inquiry about the opportunities for the Region to work with local housing corporations to coordinate support and assistance to tenants, M. Schuster stated that the objectives of the current program have been met and that staff are now developing plans for new initiatives to meet the identified needs of the community and can consider partnerships and programs with local housing corporations.

In response to a Committee inquiry about the status of current outreach programs within our social housing facilities, Lynn Randall, Director, Social Planning, Policy and Program Administration, agreed that a shift has occurred but stated that funding resources aren't available through a single provincial ministry.

MOVED by J. Wideman
SECONDED by B. Halloran

THAT the Regional Municipality of Waterloo enter into an annual agreement with Supportive Housing of Waterloo (SHOW) for up to $100,000 for tenant support at their 30 unit supportive housing program located at 362 Erb Street West in Waterloo, as determined by the Commissioner of Social Services, effective January 1, 2011, in a form satisfactory to the Regional Solicitor;

AND THAT the Regional Municipality of Waterloo enter into a one-time agreement with SHOW for $39,780 effective January 1 to December 31, 2011, in a form satisfactory to the Regional Solicitor, to support their 2011 operations transition plan;

AND FURTHER THAT Council request that the Province, through the Waterloo-Wellington Local Health Integration Network, provide on-going operating funding required for SHOW as outlined in report SS-11-034, dated September 27, 2011.

CARRIED

h) SS-11-035, Domiciliary Hostel Program Funding to Meet Compliance Standards

MOVED by J. Brewer
SECONDED by J. Wideman

THAT the Regional Municipality of Waterloo approve the expenditure of up to $100,000 in one-time funding to support Domiciliary Hostel Program operators in meeting compliance under the Domiciliary Hostel Standards, as determined by the Commissioner of Social Services;

AND THAT the Regional Municipality of Waterloo approve entering into funding agreements with operators under the Domiciliary Hostel Program in receipt of one-time funding from the Region to assist in meeting compliance under the Domiciliary Hostel Standards, in a form satisfactory to the Regional Solicitor, as outlined in report SS-11-035, dated September 27, 2011.

CARRIED
i) SS-11-036, Waterloo Region Energy Assistance Program Update

MOVED by C. Zehr
SECONDED by R. Kelterborn

THAT the 2011 Operating Budget for Social Planning, Policy and Program Administration be increased by $83,406 gross and $0 net Regional Levy to be fully funded by corporate partners;

AND THAT The Regional Municipality of Waterloo request the Ontario Energy Board to increase flexibility in program eligibility criteria for the use of funding under the Low Income Energy Assistance Program;

AND FURTHER THAT The Regional Municipality of Waterloo approve entering into agreements, from time to time as determined by the Commissioner of Social Services, generally to support the implementation of the Waterloo Region Energy Assistance Program, subject to receipt of Provincial Government funding and corporate partner funding, in a form satisfactory to the Regional Solicitor, as outlined in Report SS-11-036, dated September 27, 2011.

CARRIED

j) SS-11-037, Immigration Partnership – Waterloo Region

MOVED by B. Halloran
SECONDED by J. Mitchell

THAT the Regional Municipality of Waterloo increase the 2011 Operating Budget for Social Planning, Policy and Program Administration by $13,000 gross and $0 net regional levy;

AND THAT the Regional Municipality of Waterloo approve entering into agreements with agencies or consultants, as determined by the Commissioner of Social Services from time to time, to support the implementation of the Immigration Partnership Strategic Plan for the period August 1, 2011 – December 31, 2011, subject to receipt of this funding from the United Way of Kitchener-Waterloo and Area, as outlined in report SS-11-037 dated September 27, 2011.

CARRIED

k) SS-11-038, Additional One-Time Provincial Rent Bank Funding

MOVED by C. Millar
SECONDED by J. Brewer

THAT the Regional Municipality of Waterloo approve an increase to the 2011 Operating Budget for Social Planning, Policy and Program Administration of $10,856 gross and $0 Net Regional Levy, due to receipt of an additional $10,856 in one-time funding through the Provincial Rent Bank Program;

AND THAT the Regional Municipality of Waterloo amend its current agreement with Lutherwood to provide additional one-time funding in the amount of $10,856 for the Rent Bank and Eviction Prevention Program loan fund, for the period January 1, 2011 to December 31, 2011, in a form satisfactory to the Regional Solicitor, as outlined in report SS-11-038, dated September 27, 2011.

CARRIED
m) SS-11-040, New Infant Rate for Directly Operated Children’s Centres

Nancy Dickieson, Director, Children’s Services, advised that the infant care program is a new category of care in the Region’s directly-operated centres. The pilot program will take place at Christopher Children’s Centre and review of the program will determine if it is viable at the other directly operated centres. In response to a Committee inquiry about the proposed rate, she stated that it is in line with the local market rates.

MOVED by J. Mitchell
SECONDED by L. Armstrong

THAT the Regional Municipality of Waterloo approve an infant rate of $65.00 per day charged at the five directly operated Children’s Centres effective November 1, 2011 as outlined in report SS-11-040, dated September 27, 2011.

CARRIED

n) SS-11-042, Employment and Income Support Service Delivery Evaluation

M. Schuster made introductory comments. David Dirks, Director, Employment & Income Support, identified the evaluation participants, the outcomes and next steps to address the evaluation themes.

Received for information

INFORMATION/CORRESPONDENCE

a) Memo: Association for Municipal Employment Services Annual Conference

Received for information

b) Memo: STEP Home Video and Updated Brochure

Received for information

c) Memo: New Provincial Website for Early Learning Framework

Received for information

d) Ministry of Education Re: Transfer of Child Care from the Ministry of Children and Youth Services to the Ministry of Education

Received for information

e) Memo: Waterloo Region Museum Steering Committee

Rob Horne, Commissioner, Planning, Housing and Community Services, extended his appreciation to the Councillors who were involved on the steering committee and to the members from the community who were instrumental in the success of the Museum.
In response to a Committee suggestion that an advisory committee be established to work with staff regarding the continued development of the Museum, R. Horne agreed that ongoing public input is important.

Received for information

f) Memo: Waterloo Region Museum Public Art Dedication

Received for information

OTHER BUSINESS

a) Council Enquiries and Requests for Information Tracking List was received for information.

NEXT MEETING – October 18, 2011

MOTION TO GO INTO CLOSED SESSION

Chair Strickland advised that an additional matter has arisen and will be discussed in the closed session; he read aloud to the Committee the subject matter description for Item 8d).

MOVED by J. Mitchell
SECONDED by J. Haalboom

THAT a closed meeting of the Community Services and Administration & Finance Committees be held on Tuesday, September 27, 2011, immediately following the Community Services Committee meeting, in the Waterloo County Room, in accordance with Section 239 of the Municipal Act, 2001, for the purposes of considering the following subject matters:

a) receiving of legal advice and opinion that is subject to solicitor-client privilege related to a contract
b) receiving of legal advice and opinion that is subject to solicitor-client privilege related to a legal agreement
c) receiving of legal advice and opinion that is subject to solicitor-client privilege related to legal agreement
d) proposed or pending litigation related to a matter before an administrative tribunal

CARRIED

ADJOURN

MOVED by J. Haalboom
SECONDED by L. Armstrong

THAT the meeting adjourn.

CARRIED

The meeting adjourned at 11:04 a.m.

COMMITTEE CHAIR, S. Strickland

COMMITTEE CLERK, S. Natolochny
LYME LEAVES US SUFFERING YES, FROM TICKS IN CANADA MEDICAL HELP URGENTLY NEEDED EVER INCREASING CASES THE WALL OF HOPE
SYMPTOMS OF LATE STAGE LYME DISEASE

- The Tick Bite (fewer than 50% recall a tick bite or get/see the rash)
- Rash at site of bite
- Rashes on other parts of your body
- Rash basically circular, oval and spreading out (more generalized)
- Raised rash, disappearing and recurring

- **Respiratory and Circulatory Systems**
  - Shortness of breath, can't get full/satisfying breath, cough
  - Chest pain or rib soreness
  - Night sweats or unexplained chills
  - Heart palpitations or extra beats
  - Endocarditis, Heart blockage

- **Digestive and Excretory Systems**
  - Diarrhea
  - Constipation
  - Irritable bladder (trouble starting, stopping) or Interstitial cystitis
  - Upset stomach (nausea or pain) or GERD (gastroesophageal reflux disease)

- **Musculoskeletal System**
  - Bone pain, joint pain or swelling, carpal tunnel syndrome
  - Stiffness of joints, back, neck, tennis elbow
  - Muscle pain or cramps, (Fibromyalgia)
• **Eyes/Vision**
  - Double or blurry vision
  - Increased floating spots
  - Pain in eyes, or swelling around eyes
  - Oversensitivity to light
  - Flashing lights/Peripheral waves/phantom images in corner of eyes

• **Reproduction and Sexuality**
  - Loss of sex drive
  - Sexual dysfunction
  - Unexplained menstrual pain, irregularity
  - Unexplained breast pain, discharge
  - Testicular or pelvic pain

• **Mental Capability**
  - Memory loss (short or long term)
  - Confusion, difficulty in thinking
  - Difficulty with concentration or reading
  - Going to the wrong place
  - Speech difficulty (slurred or slow)
  - Stammering speech
  - Forgetting how to perform simple tasks

• **Ears/Hearing**
  - Decreased hearing in one or both ears, plugged ears
  - Buzzing in ears
  - Pain in ears, oversensitivity to sounds
  - Ringing in one or both ears
• **Head, Face, Neck**
  - Unexplained hair loss
  - Headache, mild or severe, Seizures
  - Pressure in head, white matter lesions in brain (MRI)
  - Twitching of facial or other muscles
  - Facial paralysis (Bell's Palsy, Horner's syndrome)
  - Tingling of nose, (tip of) tongue, cheek or facial flushing
  - Stiff or painful neck
  - Jaw pain or stiffness
  - Dental problems (unexplained)
  - Sore throat, clearing throat a lot, phlegm (flem), hoarseness, runny nose

• **Neurologic System**
  - Tremors or unexplained shaking
  - Burning or stabbing sensations in the body
  - Fatigue, Chronic Fatigue Syndrome, Weakness, peripheral neuropathy or partial paralysis
  - Pressure in the head
  - Numbness in body, tingling, pinpricks
  - Poor balance, dizziness, difficulty walking
  - Increased motion sickness
  - Lightheadedness, wooziness
• **Psychological well-being**
  • Mood swings, irritability, bi-polar disorder
  • Unusual depression
  • Disorientation (getting or feeling lost)
  • Feeling as if you are losing your mind
  • Over-emotional reactions, crying easily
  • Too much sleep, or insomnia
  • Difficulty falling or staying asleep
  • Narcolepsy, sleep apnea
  • Panic attacks, anxiety

• **General Well-being**
  • Phantom smells
  • Unexplained weight gain, loss
  • Extreme fatigue
  • Swollen glands/lymph nodes
  • Unexplained fevers (high or low grade)
  • Continual infections (sinus, kidney, eye, etc.)
  • Symptoms seem to change, come and go
  • Pain migrates (moves) to different body parts
  • Early on, experienced a "flu-like" illness, after which you have not since felt well.
  • Low body temperature

• Allergies/Chemical sensitivities

• Increased effect from alcohol and possible worse hangover
EMI AGE 2 ½
EMI’S BULL’S EYE RASH AFTER A TICK BITE
Nichole age 18, has had Lyme disease and co-infections for over 5 years.
PARKER AGE 11, SUFFERING FROM CONGENITAL LYME DISEASE AND CO-INFECTIONS
UNITING TO FIGHT FOR
LYME DISEASE AWARENESS
BETTER TREATMENT
MORE FUNDING
NO MORE LIES
ACCURATE TESTING
LYME LITERATE DOCTORS
PATIENT RIGHTS
I would like to thank the committee for inviting me to come back and speak again of the issue of Lyme disease and the numerous difficulties faced by the citizens of Ontario and this country when seeking help from the debilitating and deadly disease.

First of all I would like to thank Councillor Jean Hailboom for not accepting the original resolution when brought to the Regional council as a whole. Her recommendation that more needs to be done on a provincial level underscores what MPP Bob Bailey’s Lyme disease petition aims to do.

When I was here in August I spoke on the various problems faced by Lyme disease patients in this province and country. Today I am going to speak more about the personal experience.

I touch on my own personal battle a little in my delegation the last time I was here, today I am going speak more on my experience to help bring into focus the true horrific nature of this disease.

On the screen I have listed the symptoms of Lyme disease. It took me four slides to fit them all in. Of this list I had about 75% of them, I also had known tick bites and I had a bull’s eye rash.

When I started to get very sick with severe symptoms such as electrical shocks running through my body, burning skin that feels like someone is holding an iron on me, losing my eye sight in my left eye, heart palpitation and quivering, and choking on my food I thought I was going to die. My body which has been very healthy all my life started to complexly deteriorate. I kept going to the doctors seeking help, some tried to help but most were quick to dismiss me and in some cases treated me in a derogatory manner.

When I finally figured out myself what was wrong no one wanted to listen or help. Through the support of the Lyme disease community I was able to find a doctor in the Toronto area who was willing to try and treat a late stage Lyme patient. I started see him in Sept 2011. He clinically diagnosed me with Lyme disease and started antibiotic treatment to try and kill this bacterium.
I got sicker first due to the die off of the bacteria which is toxic when killed and then I began to get better. Many of my symptoms started to lessen and some disappeared completely. I continued treatment with my Toronto doctor until in March of 2011 he stopped treatment that he originally said may be a couple of years. Through the Lyme disease community it was general knowledge that this doctor was now being investigated by the College of Physicians and Surgeons of Ontario for treating Late stage Lyme disease due to a neurologist’s complaint to the College when a patient who was being treated for I believe Parkinson’s by the neurologist started see this Toronto doctor and began treatment for Lyme disease. When this patient started to see improvements from the Lyme disease treatment he returned to the neurologist and was angry because he never felt it was Parkinson’s but no one would listen to him. After being confronted by the patient the neurologist made a formal complaint about the Toronto doctor to the College. When I went to his office the entire office was filled with people suffering from Lyme disease. This doctor was the only doctor left in Ontario that was willing to openly treat a Lyme disease patient. Two other Ontario doctors had been brought under suspicion for treating Late stage Lyme disease in the past. Both are no longer treating. Under the threat of losing his license all of his Lyme disease patients were release if they had received the short course of treatment recommended by the College of Physicians and Surgeons of Ontario and the Public Health Agency of Canada even if still very ill.

I was forced to seek treatment in the US. I have been seeing a LLMD trained by ILADS since May. I take 54 pills a day. It has been a horrific journey. To convey how bad it got with this disease I tried to take my own life this past winter when faced with no hope of receiving medical care here in Ontario for a disease that will cause you to wish you were dead when left untreated. But through my new doctor I am getting better. I was finally about to return to work part time a few weeks ago after over a year of being unable to work. I am able to be part of my family’s life and finally life doesn’t seem as hopeless. But I still live in fear- not of the disease – I can fight that but the fear of running out of money before I am able to
get this disease in remission and being forced to abandon my US treatment and face the spiral into unimaginable hell that is Late stage Lyme disease.

I have racked up over 20000 on my LOC and I am now looking into cashing in my RRSP and possible having to sell my home to receive medical treatment that is being denied to me and thousands of Canadians in a country where universal health care is supposed to be as Canadian as the maple leaf. But it is not my plight that drives me to speak at this meeting and the various meetings I have spoken at across Ontario it is the children with Lyme disease who are suffering and who’s inhumane treatment in this province and country due to the lack of knowledge and education compels me to make my voice heard. I have permission from three moms to speak about their children who are suffering from Lyme disease and co-infections here in both our province and country.

I met Emi at a presentation I did in Middlesex. She is 2 ½. She had the tick attachment, the bull’s eye rash and the early symptoms of Lyme disease. Doctors ran the ELISA test which came back negative and have refused to treat her. Her mother has taken her to numerous physicians to no avail. Emi suffers from headaches, leg pains (bad enough that she doesn’t walk some days), ongoing stomach aches and various other ailments. Her mother is very worried that her daughter will have continued health deterioration yet is unable to access any medical help in this province. Unable to afford to seek treatment in the US Emi’s mother is watching and hoping changes will happen in this province to allow her daughter to get help.

Nichole has had Lyme disease and co-infections for over 5 years. She was part of the W5 “Out of the Wild” series that looked at the medical and government neglect of Lyme disease sufferers in this country. I included a link to the W5 program in my original package. Nichole has been confined to a wheelchair, needs oxygen, has no short term memory and suffers from daily debilitating pain. Her family has had to sell their home and is in debt over 100000 from the cost of seeking treatment in the US. The US doctors are confident that Nichole will
eventually get the disease in remission. Nichole is a fighter and an advocate for Lyme disease. She has spoken many times on this disease and writes about her struggles in her blog “Bite me”. At a time when she should be enjoying life and planning for her future she struggles to live from the bite of a bug the size of a poppy seed.

And finally I am going to speak about Parker. Parker is very ill boy with Lyme disease and co-infections. Three members in his family have Lyme disease. Parker contracted Lyme disease congenitally from his mother. They all have had to seek treatment in the US when the only doctor in BC, Dr. Murikami who openly treated Lyme disease was investigated in that province by their College. Although they could not find any wrong doing on Dr. Murikami’s part involving his treatment of Late stage Lyme disease, the doctor gave up his license after years of investigate which were beginning to take a toll on his health.

Parker is now 11. He has been unable to go to school for years now due to this disease. He too is in a wheelchair. Parker has had severe neurological symptoms including seizures, excruciating pain that is not lessen by even the strong pain medication, various issues with organs that are being affected by the bacterium and other symptoms that are too numerous to count. This poor boy has been abandoned by our medical community. No Canadian doctors want to touch him or his family as is the case with most Lyme disease patients. Parker was actually told by a pediatric doc at BCCH and I quote from his mother Shannon "I know you have a life threatening illness but I’m sorry, I can't risk my license to treat you." This child has suffered what no person should have to suffer. Only a person with Lyme disease can understand the true horrors of this disease and through my own experience which has been nowhere near what this brave boy has had to endure I am applaud. It is unimaginable that while fight a life threatening infection not only does this boy have to fight to stay alive, he has to fight a medical community and a government to receive care. Care that has been denied to him.

As recently as this past month Parker has been again rejected by the BC medical community which use the government’s position on Lyme disease to justify this
inhumanity and again his family was forced to seek medical care in the US. Imagine if it was your child.

As a country we should be disgusted by what is happening to the Lyme disease community. The stories I spoke about are only a few of 1000’s that are repeated across this country. I receive phone calls on a regular basis of people asking for help. The Ontario rep for the Canadian Lyme Disease Foundation says she gets 4-5 calls a day from people in Ontario desperate for help. There is no help here in this province as is the case across this country. The support I have received through the petition has been amazing. We have had more than 100 municipalities support the petition representing over 2 million Ontarians.

In closing I would just like to say I have often compare the Lyme disease epidemic to the AIDS epidemic in the early 80’s when no one cared that people were dying. It wasn’t until the disease started to touch everyone that people started to put pressure on both the government and the medical community. That was a shameful time, how people with AIDS were treated was nothing less than deplorable. Did we as a society not learn anything from that time -- we must not have since it is now the Lyme disease community being shunned and abandon and left to die. We need more action from all levels of government on Lyme disease and I would again like to thank Councillor Jean Hailboom for realising more needs to be done.
Good morning and thank you for allowing me to speak to you today. I have given you all a package with a pamphlet from Public Health, a pamphlet from CanLyme which is our Canada-wide support and advocacy group as well as a pamphlet from The Lyme Disease Association out of New Jersey where I happen to see my Lyme specialist.

I have also included a letter I sent back in May to Public Health asking for changes and improvements in how Lyme Disease is handled in the region along with questions that wanted answers for. Also included in the package is a letter sent to me this past August by Brenda Miller; Manager, Infection Control, Rabies, Vector-borne diseases, Tobacco Enforcement and Kitchener and Area Team explaining their role as they see it, as well as the actions they have taken on the public’s behalf. Further I have included my letter back to Brenda Miller, answering her letter to me, point by point.

I have great fear, anger and frustration around this issue since it is no longer just me who has been battling this deadly infection. I have had it for thirteen years and have been in treatment for only five of those years after being misdiagnosed with Fibromyalgia. I passed on the bacteria through breastfeeding to my two children, Elyse and James. Both are on long-term treatment for Lyme disease and co-infections that they have suffered from since they were verbal. I have to take them to Connecticut to see a Pediatric Lyme specialist since we have none in Canada, and if we did, they would not be allowed to treat them properly. We have spent in the area of $10,000 this year alone for testing, diagnosis and treatment for my family.

So let’s look at what my husband, children and I are dealing with every day while we struggle to have a good life. We are in the same boat as the thousands of other Lyme patients across Canada.

The main areas of concern regarding Lyme disease are threefold: diagnosis, testing and treatment.

Under Testing: ELISA is a test from 1982 and is not accurate or reliable. Cancer patients do not expect to be diagnosed with an unreliable test from the early 1980's so why are we using it, and worse, putting so much stock in the results?

Western Blot results are subject to the number of reactive bands found by the labs and if the number of reactive bands is under what the government
says is a positive, people are told the test is negative. It does not show the bands, the numbers of the bands, nor does it address the fact that if even one band is reactive and the person is showing symptoms, that person should be treated as they are making antibodies in response to coming in contact with the bacteria and this disease is a CLINICAL diagnosis.

Co-infections are subsequently ignored. Lyme infected ticks carry other protozoa and bacteria, which, mingled with Lyme bacteria, makes the illness much more difficult to treat and cure. Ontario does not even routinely test for Babesia anymore. Yet Canadian Blood Services asks if you have it on the application form when you give blood. Had I not gone for a U.S. test, I would not have even known that I was positive for Babesia. The worse part is that when a patient gets the ELISA and/or Western Blot test back and it's negative (as most are), the patient is told they don't have it and they continue to get worse and become chronic, thereby being misdiagnosed, seeing specialist after specialist and continuing to get worse until they die. And they do die eventually, it's just that their families are told the patient passed from ALS, Parkinson's, MS, Fibromyalgia, Lupus, Chronic Fatigue, Alzheimer's or other illnesses.

I’d like to show you how sick I used to be about a year and a half ago, before I lost my Toronto Lyme doctor, before I had IV through a picc line in my arm that helped immensely and before I was tested, diagnosed and treated for Babesia. I want to tell you that episodes like the one you are about to see happened to me at least twice a day, along with seizures, extreme fatigue and pain - constant, debilitating pain. This became ordinary for my children after a couple of years but they both had to see counselors to help them cope.

Insert footage here

Under Diagnosis:

Patients are told we don't have Lyme Disease here so even getting an unreliable test is difficult. If one can catch the infection in the proper time frame, they might get a rare positive but I have a friend who had 5 positives and still her doctor didn't believe her. Doctor knowledge and support for patients with Lyme is dismal in our region. They don't seem to know the symptoms for Lyme or for the co-infections nor do they seem to want to learn them. They do not want to test, do not want to give antibiotic treatment and even resist giving referrals. When a patient does get a referral to an
Infectious Diseases doctor, they are refused. There is not one Infectious Diseases doctor in Waterloo Region who will treat Lyme Disease or see patients for it. I had my appointment cancelled when the specialist found out I had Lyme disease. He said it was not his area of interest.

Education on symptoms is very important because Lyme is a CLINICAL diagnosis yet doctors insist on having a positive blood test in the patient file before they treat! They are not willing to treat based on a clinical diagnosis, even when patients bring in articles that defy their logic or they actually show them a Bulls eye rash or bring in the tick. Even though the Ministry of Health and Long Term Care issued a letter to that effect to every Ontario doctor. They cite reasons like long-term antibiotics are bad for the body. I guess they don't worry that without them the patient gets worse and worse until they are so chronic they need years of treatment to get back to normal if they ever do. They don't seem to realize that antibiotic treatment for acne is three to six months long either. They say they don't want to be involved with Lyme, or they aren't comfortable treating because they don't know enough about it. The reasons are endless and none of them make any sense to the patients who need help immediately.

The belief that chronic Lyme doesn't exist comes from the Infectious Diseases Society of America (IDSA) that makes that claim mostly from research from their own panel of doctors. The majority of those doctors were revealed to have had conflicts of interest and an anti-trust investigation was launched against them and a whole new group of doctors put in, but new guidelines were never written but Ontario and all of Canada still use the old flawed ones! International Lyme and Associated Diseases Society (ILADS) and other independent research groups from around the world were and continue to be ignored by those in power regarding chronic Lyme, even though research out of Columbia University Lyme Research Centre states that chronic Lyme exists and long term treatment is indicated.

Ontario doctors are either too scared or are woefully ignorant as to what patients need. They can place their licenses in jeopardy if they treat according to ILADS protocol, which actually works instead of following the College's inaccurate following of flawed and biased IDSA treatment protocols. That just happened to most of the Waterloo Region patients who were being seen by an Infectious Diseases doctor in Toronto. The complaint to the college about our doctor was made by another doctor – not by a
patient. We were all getting better. We all go to the U.S. now if we can afford to. Some cannot. Canada needs to protect their doctors for treating patients long term, especially when the treatment is proven to be working.

So patients have to go to the U.S. for proper testing, ones that show which bands are reactive, and they have to take them to a U.S. Lyme specialist because Canada doesn't have one. Also, there is not one Pediatric Lyme Specialist either. Families are forced to seek diagnosis and treatment outside of Ontario and outside of Waterloo Region if they want to live. It is unacceptable.

Under Treatment:

Once a patient has run the gambit of specialists, misdiagnoses, lack of treatment and so continues to get worse, they begin to research their symptoms themselves. They are led to Lyme. Their doctors don't support their concerns, their test comes back negative and they are told it's in their head. They continue to get worse and start looking for help from other people not in the medical arena. There they are told they have to get tested in the U.S. and the best Lyme lab in the U.S. and Canada is recommended. They pay about $400.00 for a Lyme panel and the same for a co-infection panel. They still have to have a doctor here give their address so the test kit can be sent to the doctor's office. They still need a doctor here to sign the requisition form. Many people go to Naturopaths because their doctors won't even do those things for them.

It might shock you to know that veterinarians and dentists have treated family and friends in our region because our doctors won't. How embarrassing for our medical community.

Once they get results, if they have reactive bands or a full on positive, they have nobody to turn to, to help them understand what that means or what they should do about it. They ask other patients again and U.S. doctors are recommended. They must be ILADS trained. Lyme patients will not see any Lyme doctor who does not know ILADS treatment protocols. There are a number of states in the U.S. that have passed doctor protection legislation due to the large numbers of patients and the number of doctors saying IDSA protocols don't work. Waterloo Region patients only go to doctors in the protected states. They pay thousands of dollars to see a Lyme Specialist and finally, they are told, yes you have Lyme and yes you have co-infections and yes, I can help you. What a relief to these people. You can't imagine
knowing you are dying one day without help from your own medical community and the next you have hope, albeit from another country. The problem arises again when a patient needs medications to treat the illness. They need a doctor in Canada to rewrite prescriptions or insurance won't cover them. Everything then has to come out of pocket. People are in danger of losing their homes, their children do without and patients can't work since they are so sick that the burden is left to the rest of the family or spouse. Mental health issues and divorce can arise as well as poverty.

There is a movie called "Under Our Skin" out of the U.S. It's an award winning documentary about Lyme but the situation very much applies to Canadian patients. I would hope that anyone who has any input into how Lyme disease is handled in Waterloo Region has seen the movie and researched documents and articles from ILADS doctors and other Lyme literate countries as well as the government party line from the CDC who supports the guidelines so far. Things are changing, however, and there are lawsuits breeding as well as the questions, ‘who knew what and when’.

The CDC reports 395,000 new cases of Lyme Disease every year. That is more than Avian Flu, West Nile and AIDS combined. This is caused by a bug bite leaving people with a bacterial infection that results in debilitation.

Patients who are citizens of Canada have a right to health care the same as any other Canadian. If this were happening to cancer patients there would be an uproar. If doctors refused to treat or even learn about cancer it would be an uproar. If tests from the 1980's that were old and unreliable were used to diagnose cancer, there would be an uproar. If people could get cancer from a tick bite in our area, there would be an uproar.

So why are Lyme patients treated this way?

As more and more of us become chronic and our families and friends are affected by Lyme, more and more pressure will be brought to bear on the College, on Public Health, on doctors and on the Ministry of Health as well as officials like yourselves, to take responsibility for this health epidemic and to rectify it. This is not an issue that is going to go away, but will only get worse. People are devastated and angry and feeling betrayed by every level of government and the medical community. As more government employees and doctors' families contract Lyme Disease we are sure this will
change, however, for those of us who are not related to a politician or a doctor, we need change now.

I ask that you revisit the decision not to endorse the petition and if that is not going to happen, then please consider allowing others who have a vested interest in Lyme to form a task force to work with Public Health as they write another recommendation. I am not convinced that Public Health is an unbiased or blameless body of government that will amend your recommendations with the patients in mind.

**Look at my children and ask yourself that if it was your babies standing here, if you wouldn’t move heaven and earth to cure them.**

That is what I’m trying to do here today and I thank you for reading the package and for listening to my story.

With respect,

Wendy Woodhall
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Primary Partners:
• Community Garden Council
• Opportunities Waterloo Region
• Region of Waterloo Public Health

Secondary Partners:
• Municipalities
• Faith communities
• Funders
• Not for profits
• Businesses
• Universities

43 gardens
900 garden plots
13,000 volunteer hours

Patchwork Community Garden - EMS site, Waterloo
Board of Health Objectives

- Promote healthy eating and active living
- Increase capacity of community
- Create healthy supportive environments
- Support healthy public policy

Corporate Strategic Plan

- Environmental sustainability
- Growth management and prosperity
- Healthy and inclusive communities
Our Current Projects: Welcoming and Inclusive Community Gardens

Accessible Gardens
- 4 gardens
- $140, 400.00 over 2 years

Multicultural Gardens
- Cedar Hill
- Patchwork gardens – Northdale and EMS
- Vermont Park and Ecole L'Harmonie

Media Coverage
- CTV Province wide, June 5

Waterloo Regional Police Garden Allotment Program, Cambridge
Thank-you!