ECHO+ COMMUNITY REPORT 2020–2022

WELCOME TO THE ALBERTA ECHO STORY

EXECUTIVE SUMMARY

Hepatitis C is a blood borne virus spread through blood-to-blood contact causing liver disease and damaging liver tissue ultimately impacting overall health. Access to specialist treatment has been limited for many communities in Alberta even though treatment is available and has high cure rates. The ECHO program was initiated in 2015 by Dr. Sam Lee to improve access to care and was expanded with collaboration and funding through a Health Innovation Implementation and Spread (HIIS) grant in 2019 to scale and spread and became known as ECHO+.
This collaboration supported implementation of the Community Prevention Practitioner (CPP) roles and extensive community engagement to increase awareness on hepatitis C and support increased access to treatment.

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Photo credits: Kate Dunn

ACKNOWLEDGMENTS

We would like to acknowledge that the administrative work of this program takes place on the traditional meeting place known as Mohkinstsis or today known as Calgary, which is home of the Blackfoot people and the people of the Treaty 7 region in Southern Alberta, which includes the Siksika, the Piikani, Kainai, the Tsuut'ina and the Stoney Nakoda First Nations. The City of Calgary is also home to Métis Nation of Alberta, Region 3. We are grateful for the opportunity to live, work and play on these lands.

The ECHO+ team acknowledges this program and the collaborations, support and initiatives would not have been possible without the support of Indigenous community healthcare teams, and Indigenous communities and community members within Treaty 6, 7 and 8, and the Metis Nation of Alberta and Metis Settlements in what is known as Alberta. We are very grateful for the opportunity to work with you, and learn from you, and support a wellness journey.

We are grateful to the Health Innovation Implementation and Spread (HIIS) grant funding opportunity in partnership with Alberta Health and Alberta Health Services.

Collaborations and connections between many organizations have contributed to the positive impact of the ECHO+ program in Alberta.

INTRODUCTIONS

DR. SAM LEE AND THE ALBERTA ECHO STORY

When Canada was creating the Hepatitis C taskforce in the 1990's, professionals involved in hepatitis C care across the country collaborated to increase awareness on supporting the patient experience. Dr. Lee was acquainted with colleagues working in public health on the taskforce and through this connection met their family members who happened to be from a Cree Nation in Alberta. Casual conversation led to sharing a more personal story, involving leaving home as a young teen to live the street life with his two brothers, which ultimately led to infection with Hepatitis C for all three. At that time, the oldest had received treatment with interferon but was unsuccessful in sustained viral response or cure, and was beginning to feel the effects of the resulting cirrhosis, Dr. Lee immediately referred him to a specialist in his healthcare region to receive the newer and more effective treatment which; ultimately resulted in his cure. Years later Dr. Lee was consulted on a terminal patient with comorbidities alongside their hepatitis C infection, although the patient passed on this brought the oldest brother to Calgary for the memorial services and the discovery through a conversation over coffee that this had been the second brother. During the course of this conversation it was discovered that the youngest brother also had hepatitis C and although being scheduled to see Dr. Lee had not shown up for his scheduled appointments. The oldest brother immediately re-connected him with Dr. Lee and stressed the importance of immediate treatment which Dr. Lee was happy to support. As a symbol of appreciation for the support toward those in his family and to inspire a passion to make a difference in access to care for Indigenous communities the oldest brother gifted an Eagle feather to Dr. Lee.

Through this friendship the barriers to care and cure for hepatitis C within Indigenous communities became alarmingly clear to Dr. Lee and the idea to explore technology options to increase access to specialist care and make a noticeable difference in the number of people cured from hepatitis C.

Summer of 2015 Dr. Lee and a colleague from British Columbia traveled to Albuquerque, New Mexico for a weekend training on how to replicate the ECHO program for usage in Canada. Followed by emails sent to Indigenous communities, and a letter styled 'Dear Colleague' sent to Alberta Family Practitioners, as well as various professional networks contacted by phone. November 2015 the first ECHO Alberta session was held on Zoom where 2 cases were presented for consultation and prescriptions written for a treatment plan leading to cure.

Although the provincial specialist model of care may be effective for urban populations the rural community patients often fall through the gaps in this system and are lost to follow up. The ECHO model utilizing Zoom technology and access to specialist care via twice monthly virtual sessions removes some of these barriers. Uptake on this model of care was slow in Alberta. Networking with pharmaceutical professionals on community awareness projects, spreading the word through Alternative Relationship Plans (ARP) presentations, email invitations to community health centres, and First Nations Inuit Health Branch (FNIHB) leadership support, was not increasing community awareness or program uptake. Although the need was recognized, a barrier to care identified, and an opportunity or remedy provided there was still a gap in engagement, the approach was lacking in personal connection and a foundation of building a relationship with Indigenous communities.

Following conversations in 2018 with a colleague from Alberta Health Services Communicable Disease Control who was working on a Provincial Operational Strategy and Action Plan for Sexually Transmitted Blood Borne Infections (OSAP STBBI) a plan was initiated to facilitate introductions between the ECHO program and Indigenous communities. Several Liver Health Seminars were organized with Indigenous communities in which presentations by Dr. Lee were delivered on liver health and hepatitis C. Subsequently, collaboration conversations with the Scientific Office of the Population, Public and Indigenous Health Strategic Clinical Network (PPIH SCN) realized the need for increased awareness, education, support and access to care. They supported creation of a proposal for Health Innovation Implementation and Spread (HIIS) grant funding to support scale and spread of the ECHO program in Alberta. This led to the evolution from ECHO to ECHO+, with goals to expand care to multiple sexually transmitted blood borne infections (STBBIs) and an opportunity for utilization of this model of specialist care being offered to all Indigenous communities in Alberta. Through changes within the structure of Alberta Health Services, the Scientific Office of the Indigenous Wellness Core (IWC) emerged and continued to support the ECHO+ program.

INTRODUCTION TO ECHO ADVISORY COMMITTEE

The ECHO+ advisory committee included representation from Alberta Health Services Indigenous Wellness Core (AHS IWC), Provincial Population Public Health (AHS PPPH), Communicable Disease Control (AHS CDC), University of Calgary Cumming School of Medicine Liver Unit (UofC CSM), Indigenous Community representative, Alberta Cancer Prevention Legacy Fund (ACPLF), Digestive Health Strategic Care Network (AHS DH SCN), and Indigenous Services Canada (ISC).

Indigenous community representatives provided cultural guidance and traditional protocol within the advisory and participation throughout the project.

Advisory committee members were invited to attend monthly virtual meetings. These meetings included project updates, plans for project implementation, discussion on potential collaborations, and reports from aligning provincial projects.

ECHO+ TEAM

The ECHO+ team included leadership from the Alberta Health Services Indigenous Wellness Core (AHS, IWC) Scientific Office, including Melissa Potestio, Richard Oster, and Kienan Williams. The day to day engagement team included Kate Dunn as Community Integration Lead and two community prevention practitioners (CPPs), the North portion of the province represented by Karen Delina and the South supported by Sandie Scalplock. This team focused on building relationships with communities through phone calls, emails, and visits to increase awareness of hepatitis C and the importance of screening, treatment and cure.

The Community Prevention Practitioner (CPP) role, established through the Alberta Cancer Prevention Legacy Fund (ACPLF) First Nations and Cancer Prevention and Screening Project, was key to the success of the ECHO+ project. A primary aim of the community prevention practitioner (CPP) role is to work as a liaison and to facilitate the implementation and evaluation of the ECHO+ model with Indigenous communities. From establishing trusted working relationships with members of the community, to supporting healthcare staff in recognizing opportunities to integrate hepatitis C screening and treatment, into their programming, the community prevention practitioner (CPP) role provided increased capacity for communities to carry out the goals and objectives of the program. Community prevention practitioners (CPPs) also supported development of culturally relevant hepatitis C resources, and, assisted in facilitating in-service training to community-based staff, health professionals, managers and individuals.

MEET THE ECHO+ TEAM

Mellissa Potestio, PhD.
Scientific Director

Richard Oster, PhD.
Scientific Director

Kienan Williams
Assistant Scientific Director

Kate Dunn
Community Integration
Coordinator

Karen Delina
Community Prevention
Practitioner North

Sandra (Sandie) Scalplock
Community Prevention
Practitioner South

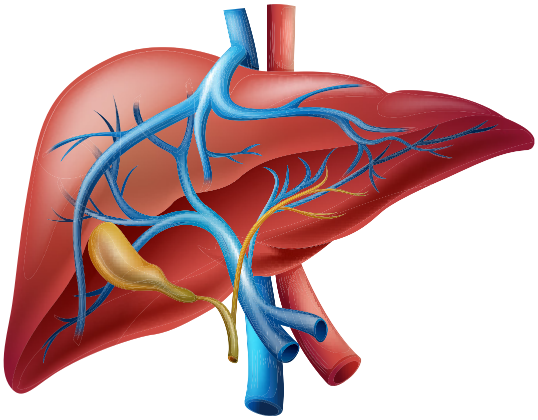
HEPATITIS C AS A HEALTH CONCERN

The liver is an important part of the body, in fact you cannot live without a liver. The liver does over 500 jobs in the body and there are several things that can cause an infection or inflammation in the liver which is called cirrhosis. One of the things that can cause this is hepatitis C. This is a virus that was named in 1989, and is passed by blood to blood contact, there is no vaccine for this virus, but there is a cure.

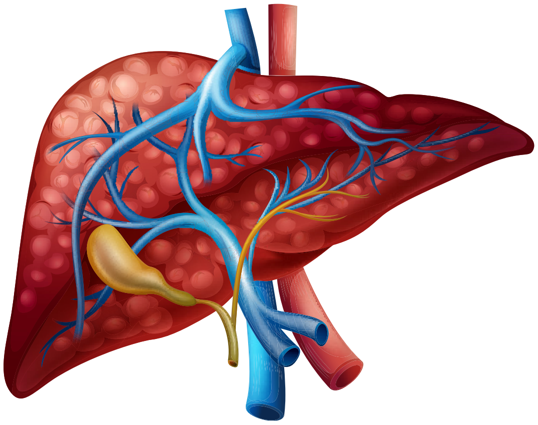
Exposure can happen through blood or blood product transfusion before early '90s, non-sterile dental work, mother to baby infection during pregnancy or delivery, sharing of needles, straws, pipes, or other substance works, non-sterile tattooing or piercing, manicure/pedicure, sharing toothbrush, clippers or razor with infected person. Although hepatitis C is stigmatized as a 'sex disease' it's rare for an exposure to happen that way. Immunizations at residential school with a shared needle, non-sterile dental work as a child, blood transfusion for an accident when you were a teen, sharing a cooker or needle when using substances, a friend giving you a tattoo or piercing, or even getting your nails done where they didn't sterilize the cuticle scissors are examples of ways you could have been infected with the hepatitis C virus. It only takes one exposure, and you may not remember it, in fact you may not even have any idea of the infection for 20 years or more. Nearly half of Canadians who have hepatitis C do not know they have it. This creates a public health issue and leads to more life years lost than any other infectious disease in Canada (2). This is why screening is so important.

If untreated the hepatitis C virus causes tissue damage in the liver that may lead to cirrhosis, hepatocellular carcinoma or liver cancer and the need for a liver transplant.

Hepatitis C infections represent a major public health burden in Canada even though effective treatment is available with high cure rates following a few weeks of medication. Stigma, lack of public health awareness, knowledge gaps with primary care providers, along with poor follow-up or limited access to hepatitis or liver specialists result in poor treatment outcomes (3). In a large research study in Alberta with 6154 people, only two thirds of patients were tested for hepatitis C, and only one third was assessed by a hepatitis C care provider with just over 3% achieving cure within two years of diagnosis (3). Alberta has a hidden and rising burden of sexually transmitted and blood born infections (STBBIs)(4) and hepatitis C in particular, the prevalence rate is four times higher for First Nations as compared to all Albertans (5-7). A lack of access to culturally safe and appropriate prevention, screening and treatment services is a root cause of this avoidable hepatitis C burden (6). The ECHO+ program offers access to treatment for hepatitis C that removes barriers and supports community access to supportinve care and cure.



Normal Liver



Liver with Cirrhosis

WHAT DOES MY LIVER DO?

- Filters blood coming from digestive system
- Makes proteins that help digest food and stop bleeding
- Stores vitamins and minerals
- Boosts the immune system
- Changes medications into usable form
- Filters toxins, alcohol, drugs and other chemicals

ECHO TO ECHO+ EXPANDING THROUGH COLLABORATIONS AND RELATIONSHIPS

ECHO+ OBJECTIVES

Project objectives and proposed impact for the initial Health Innovation Implementation and Spread (HIIS) ECHO+ funding proposed;

1 To partner with Indigenous communities to tailor and implement the ECHO+ model in an effort to reduce inequities in the identification and treatment of hepatitis C and other sexually transmitted and blood borne infections (STBBIs).

2 To develop strategies, resources and interventions that incorporate Indigenous oral knowledge and western written evidence into the development of an expanded ECHO+ model.

3 To rigorously test and evaluate the impact of spreading and scaling the ECHO+ model to Indigenous communities using a mixed-methods approach.

COLLABORATIONS

Collaboration has been an important part of the ECHO+ program and this is evident in the timeline of engagement from the program inception to the point of growth and increased utilization. Connecting with communities across the province and offering virtual awareness presentations during the pandemic, co-creating awareness media and printed material, and supporting community events has created opportunities to work together in increasing awareness about hepatitis C and the need for screening as well as linking people to the ECHO+ program and Zoom sessions for access to treatment.

Early collaboration with team members from the Communicable Disease Control of Alberta Health Services led to increased introductions, connections and trust building in the ECHO+ approach to specialist treatment through technology for remote communities.

Further collaboration with the Alberta Cancer Prevention Legacy Fund (ACPLF) and the shared learnings of the community prevention practitioner (CCP) approach created an opportunity to model this role in engagement with remote communities in the North as well as the South. Supporting capacity to build stronger relationships supporting awareness of the ECHO+ program as well as the importance of hepatitis C education and screening.

Partners in education, awareness and networking for increased access to screening include the Alberta Health Services SCNS, the National Microbiology Laboratory, and industry partners including Abbvie, Gilead, London Drugs, Lupine and Intercept who supported the annual ECHO+ Conference and community education events.

PROGRAM DESIGN

Deployment of the ECHO+ program was started with the creation of the ECHO+ team. Hiring Indigenous persons to support community engagement and relationship building in the positions of Community Prevention Practitioners (CCP), Community Integration Lead, and Project Director shaped not only the day to day tasks but also the approach methodology.

Meeting the project objectives was achieved through six work streams or areas of focused activity: 1) Engaging and developing trusting relationships; 2) Resource and tool development; 3) Implementation of the ECHO+ model; 4) Expansion to include screening for other STBBIs; 5) Sustainability planning; 6) Knowledge Translation and Evaluation (see Figure 2).

The Truth and Reconciliation Commission of Canada encouraged the use of the "Five Rs" design: Respect, Relevance, Reciprocity, Responsibility, and Relationship in its calls to creating positive changes in healthcare barriers and improving health equity (13). The ECHO+ project was guided by the Five R design as core principles, while working within a Two-Eyed Seeing approach.

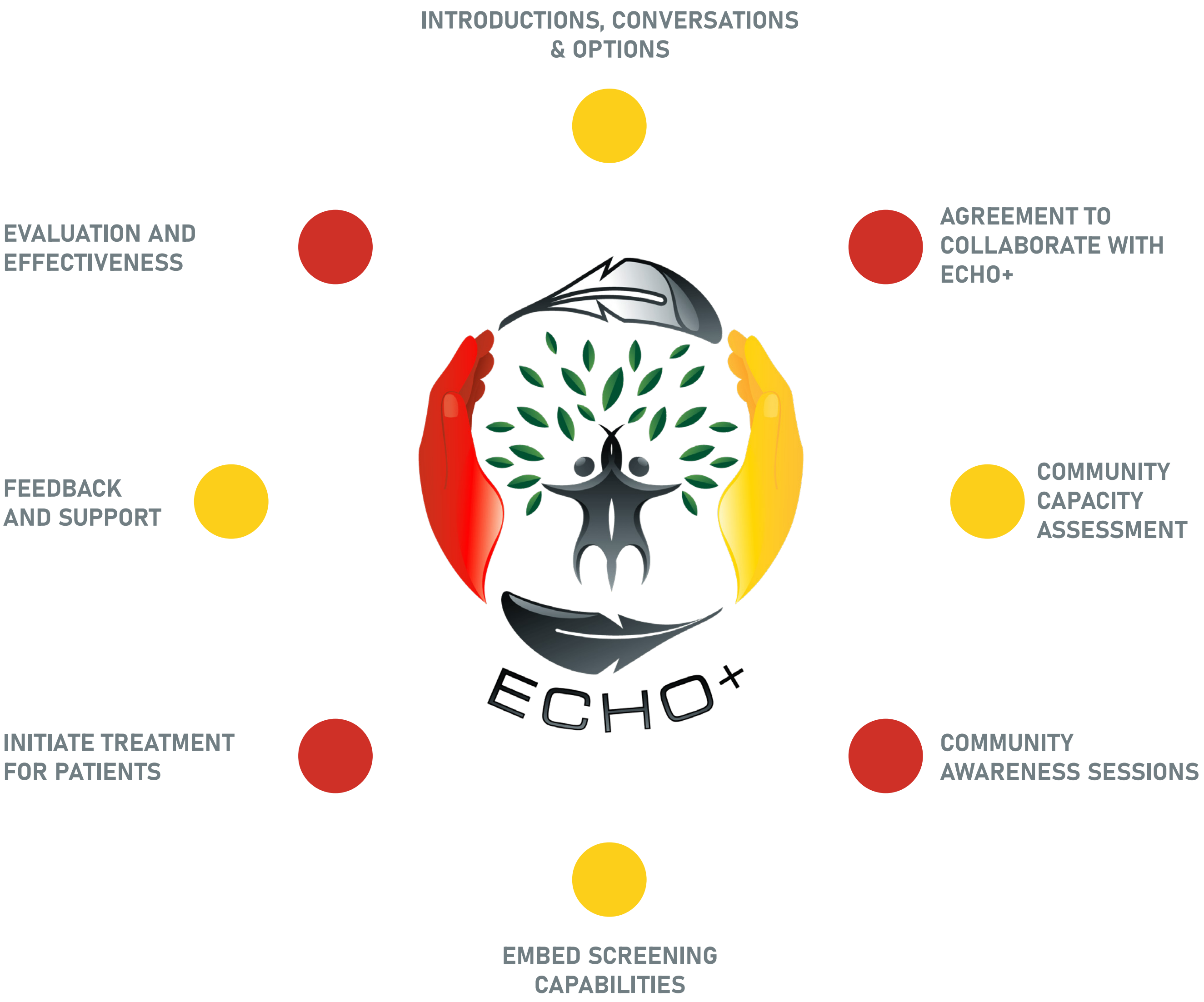
Relationship is not only the basis of effective and impactful project design but also a necessity in recognizing the rich cultural beliefs, concepts, ceremonies, and practices relevant to community health and wellness (14-16). Respect means living this relationship in all interactions with a "good heart," modeling honesty while humbly guaranteeing good motives and actions toward all stakeholders or participant partner communities involved in the program. ECHO+ incorporated these values with the Two-Eyed Seeing perspective by including and respecting the perspectives from "both eyes" in knowledge building, design, and approach, thus creating a shared collaboration process while acknowledging First Nation and Metis worldviews (17, 18).

Figure 2: The Five Rs design supporting the Two-Eyed Seeing framework in community approaches to hepatitis C care. The five core principles work as the foundational hub (inner circle). The work streams (outermost arrows) reflect the five categories of funding requirements. Western written evidence, combined with community-directed priorities, oral knowledge, and the Indigenous perspective of wellness (slices of the circle), create a circular iterative model to expand hepatitis C awareness and treatment within communities.

ECHO+ embodies this perspective by combining community-specific feedback and direction with scientific approaches while maintaining a focus on the Five Rs to build a circular, iterative model expanding hepatitis C awareness and treatment within communities (Figure 2) (15, 16).

Equally important in project integration was the incorporation of best practices from Indigenous research methodologies such as the principles of OCAP: Ownership, Control, Access, and Possession (FNIGC.ca). Implementing a project with OCAP compliance protects Indigenous community information, data, and knowledge shared with the ECHO+ team (20). The project team implemented the principles of OCAP in design, data collection, and reporting of the ECHO+ project.

CIRCLE OF SUPPORT FOR HEPATITIS C TREATMENT



Circle of Support for interested communities.

Each community is supported by a varying team of health care personnel and differing jurisdictional guidelines. To support this the ECHO+ team fostered a relationship with the healthcare team members to facilitate awareness, education opportunities and team support when there were questions, concerns or local issues. This approach recognized that each community has different needs and capacity, and thus some communities are fully engaged and currently screening, presenting cases at the ECHO+ biweekly Zoom sessions and following through with treatment and cure. This provides an approachable, informative and practical program appeal so that when the pandemic eases these communities will be ready to engage at the next level and increase screening and treatment of hepatitis C.

> *“Only good to say about ECHO, biweekly sessions are very helpful, we learn so much from the other communities and on the disease itself, and the unique history and unique presentation of each patient so we learn how to navigate it for our patients.”*
>
> *“The monthly newsletter is so helpful as well, you suggest events and learning resources or opportunities that we wouldn’t learn about otherwise, this is very helpful and supportive.”*
>
> *“Pamphlets were great”*
>
> *“Fabulous as a resource, the education stuff was great, the info on workshops and conferences and ongoing events, the handouts, Myth versus Fact booklet and the resource connection to CATIE. No gaps noted in the resources, they were amazing.”*
>
> *“The ECHO program is great, really good awareness thru newsletter and invitations to case presentation, looking forward to the fall conference, really appreciate the resources, the easy access to specialist and I know exactly who and how to find you when I have a case or a question.”*
>
> *Community Survey Responses, Spring 2022*

CREATING STORY TOGETHER

ECHO LOGO CO-DESIGN

Requests for a symbolic logo were taken to the ECHO+ team who worked with an Indigenous artist and Knowledge Keepers to co-design a logo. The logo illustrates the importance of respect, relationship, healing hands, collaboration, life-giving land-based connections, and colors or symbolism of the medicine wheel. ECHO+ working alongside communities in respect and mutual appreciation for what we can do together to create a safe space increasing access to healthcare and supporting a journey to wellness.

SUPPORTING THE STORY

Conversations with Indigenous community members who shared their living experience stories and inspiration to encourage others to follow through with screening and treatment. Knowledge Keepers or Elders also shared stories and perspectives related to traditional health practices and liver wellness which were shared widely over the course of several months in the ECHO+ newsletter across the province.

STORIES ARE A POWERFUL ASPECT OF WELLNESS AND THE NEXT FEW PAGES INCLUDE STORIES, MEMORIES AND PERSPECTIVES SHARED BY KNOWLEDGE KEEPERS, ELDERS AND THREE COMMUNITY MEMBERS WHO HAVE SHARED THEIR LIVED EXPERIENCE STORIES WITH HEPATITIS C.

WE ARE GRATEFUL FOR THE WISDOM AND EXPERIENCE SHARED HERE.

WELLNESS PERSPECTIVES

It's beautiful to have the teachings from the Grandfathers and the Grandmothers, what goes on in each season, what to dig out in the spring, what it's good for, all these things were told to the people.

Look at all the people who lived into their 90's. They always had something boiling, even just a pot of water and that steam cleanses the house, even what is hidden from our eyes but always cleansing the air. Because of this steam their lungs were clear then their minds were clear. Water is a healer.

Your mind is a healer that is why you have a mind. When you take a drink of water close your eyes and see where it runs through your body, make it go the right way, watch it giving life. Your mind is your healer, your mind is a gift from the Creator and he gives us that mind to generate it, and to generate it means being good to it. Your mind is your healer.

The wind that cleanses, the wind that everybody hates, I used to do the same thing and complain about the wind but now I realize the wind is cleansing what is not supposed to be on Mother Earth, it pushes the bad things along, it cleanses, clears up, and brushes out. Wind can be a healer too.

Plants are there to help what is bothering different parts of the body. Sage is a medicine and a cleanser. I had a big blister because I tripped on the sidewalk and my shin hit the curb and peeled back my skin. We put stuff on it and bandages but it wouldn't heal up. Finally I went to the doctor, and he started giving me stuff but still it wouldn't heal so he sent me to the specialist, but he didn't know what to do either. When I got home I boiled water and while it was boiling I threw sage in after thinking what would Grandmother do? I drank some and I also poured it into a great big pail, and put my whole foot in there. I did this about 10 times and the skin grew back, and even the doctor believed. You don't have to be sick to drink sage, it's always good to drink sage because it opens your pores and things start working again.

It is your mind that will drive you and direct you to which plant you are going to take. When you go back to the past, was there a doctor? Yes but you couldn't go because it was too far away. So what did they use? Tea! I drank tea when I had a cold, or when it was coming on. Grandmother would boil water, and put tea in there, sit me down and watch me drink it. What is in that tea? It's the plant medicine that they were using. There are Cancer medicine plants, cleansing medicine, appetite medicine and more. The bark of the tree while still green that cures cancer, Grandfather calls the people and tells them this is the one you need to use for this sickness. This is going to be lost, if it's not told.

Nature is the seed of life. Without Nature where would we be? Nowhere. When you find the plant you put the tobacco there and you tell the plant that you need it for a particular reason. Then you get the whole plant, you get the spirit of it. It's the same with you, you need the whole Spirit or you wouldn't be able to talk or do anything. You take the plant and you thank the Creator, you don't pray you just talk to him and tell him you need this plant to come with you, and you have left tobacco there. You take the whole plant and cut it, it will cleanse you and it will give to you and what does not belong in your body it will pick up and drain out (so make sure you are by the washroom). Something that affects your liver and your kidneys is the plastic on everything, get rid of the plastic bag around the tea because you are drinking it. The plant is natural, you are not natural. Use the plant in its natural way and then it will help the body the way it is supposed to. Plants are a healer.

The first drink comes to your liver, the carrier, the balance of your body. Lots of people left this world because of a liver problem. Alcohol has a big role in this. Coffee is just a traveling thing to carry you to the next town, so to speak. Tea generates you right into the bathroom, so that what does not belong in you will pass right away. The real poison that a lot of people have is alcohol they get bloated and then have cirrhosis.

We need to go back into the sweat where the pores open up and there is no virus in you because it will take all the pollution out of you. When you come into the sweat, you are coming back into Mother Earth's womb and you are reborn, there are things in there that you cannot accomplish out here that's why you need to keep coming back. There are things we have done wrong to our body, that's why we need a do-again. To get reborn again that's what sweats are. Life has changed, but life can change again, we can all do that and we can teach one another and go back to the old ways. We can be easier on ourselves. We need to teach our kids the healing ways.

Shared by Maurice Little Wolf - Piikani Nation

PEOPLE DON'T UNDERSTAND. THIS INFECTION IS CURABLE. I KNOW THERE IS STIGMA BEHIND IT, SOME THINK EVERYONE IS GOING TO JUDGE YOU FOR HAVING IT OR TAKING THE MEDICATION FOR IT. DON'T BE SCARED. TREATING IT IS A GOOD THING AND IT IS GOING TO CHANGE YOUR LIFE. DON'T BE SCARED.

Encouragement from MR

IN PARTNERSHIP

The only way we can tackle Hep C is to find the words in our own language that describe the relation or connection to the body. What does this disease mean? How does it travel in the body? What organs does it affect? When we understand that Hepatitis C travels in the blood and affects the liver then we will be guided to the traditional medicine that will help and the traditional ways of healing. If we can do this with our language, then it makes more sense, it flows, it becomes spiritual, there is hope, the treatment will work better and they will be cured. Each language has a name for these things in Cree, Blackfoot, Stoney, and English, we need to start making these connections to the source and the journey the virus takes in our bodies. Many people don't know the words or have the connection so when they try to fix the disease it doesn't work because they do not understand the journey of the virus.

Hep C is a negative one, so we need a good one to take that out. We can talk about this virus and learn about it in relation to its journey and the traditional medicine that will help a person but these are shared points of view they are not written down or owned by anyone. There are ways of prevention (people may have their own sacred medicines) or we do a sweat and then we are given direction on what to do. It's so important to do the ceremony and to listen. Don't change the health book that you have, the things that are in English, the things that are saving lives … But we need a different way to bring this to the people, to honor the sacred part of it.

When this partnership work begins and we honor one and honor the other, as we join hands working together it is not one sided anymore there is respect from both sides, the doctors, the nurses and the elders in partnership. When we do this work together it becomes sacred and we must respect the people that do this partnership work to bring an understanding of what Hep c is all about, we understand there has to be a partnership with it, to understand it from a western point of view and a traditional point of view then we can work forward to understand. When we show this compassion and work to grow together in our understanding so people can be supported to be free, the only way we can do this is to honor and respect each other for what we do in life. When you put it in that way, then there is always a medicine out there that can ease the pain and help.

When you talk about health issues like Hep C in my language, about what this means in relation to the body and the hope that a partnership of working together brings, then the fear that comes with a medical diagnosis that we do not understand are not the focus. Instead when we respect the meaning and partner together to put the words back into connection with our own language and our bodies, then even our children will understand what this means. We can learn the truth through natural law and find balance within both systems, the Western point of view and the Traditional point of view partnering together, and when you put it in that way, then there is always a medicine out there that can help, and ease the pain, and give hope.

With proper Traditional protocol and respect to the Elders, we can start this Journey with Honor in the Creators name.

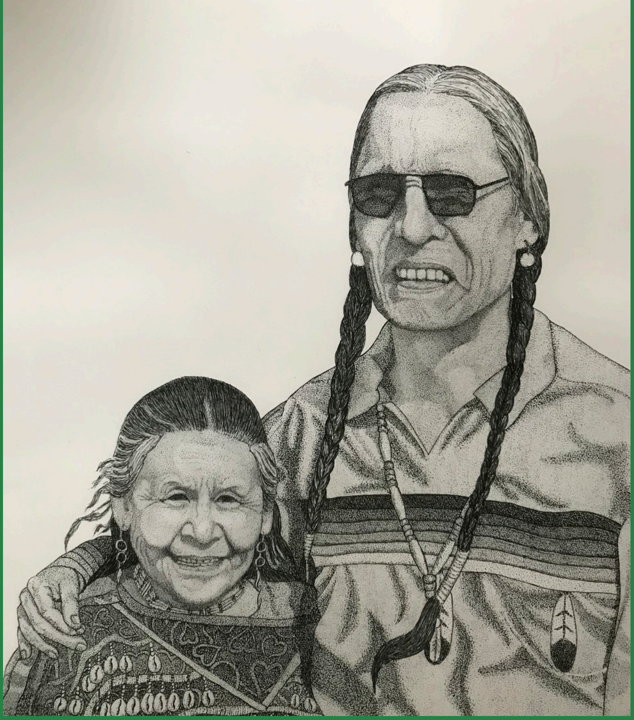
Shared by Bob Cardinal, Enoch Nation

OKI – KI?SUKKYUKIT (HELLO)

My name is Beatrice Lum now Bull Shields, I married Charles Bull Shields of the Blood Tribe in 2011. I was born in December 1945 just North of Cranbrook BC. I am from St. Mary's Band, one of three bands making up the Kunaxa Nation (Kootenay). I lived with my parents and brother until my Dad passed away when I was 8 and we moved in with my Grandparents. My Grandma raised me with our beliefs, values and ways of life, but it wasn't till I put alcohol away that I really began to see it, thank you Grandma. My Grandma had two strokes which affected her ability to walk, talk, and remember her family. Don't be in a hurry to grow up, like I was, take the time to spend with your grandparents. Listen and observe, they have a lot to teach. My Grandma passed away in 1969 and I was so involved in alcohol that I didn't even make it to her funeral. To this day I feel bad about what alcohol took from me. She told me one day, "come I'll teach you to bead, that way you can make your own spending money". Thank you Grandma because today it still helps me. I wish I had taken more time to learn the big stuff, like gloves and jackets, vests, and moccasins. That's why I say take the time.

I had four children, three who passed away. Now I have one daughter and two girls and two boys who I adopted when my Brother and his wife passed away. When my mom passed away in 1967, I just up and left, going to Spokane, Washington where I lived for 17 years and found work as a barmaid. In 1974 Charles and I crossed paths when I carded him and he didn't have I.D. so I wouldn't serve him.

My life in Spokane circled around alcohol and pills. As a barmaid I would open at 6:00 AM and would shoot speed to keep me going through my 8 hour shift and after I got off work it would be party time. This cycle led me to suicide attempts, not knowing who I really was and why I was here, wanting to be with all my family, parents, grandparents, brothers and sisters who had all passed away. During this time I likely became infected with Hepatitis C through shared needles.



I want to thank my husband, Charles. We met in 1986 and have been together ever since. He helped me raise my six children and even though we went through some hard times with alcohol, with Creators help we were able to make it through. Now Charles is a member of the Horn Society and our spirituality has become clearer and stronger. Putting alcohol away was the biggest part for us finding our way back.

I was diagnosed in 2013 with Hepatitis C and I was one of the fortunate ones whose immune system overpowered the virus and was cured. I really didn't know much about Hepatitis C until we were asked to attend a HepMEP meeting (Hepatitis Micro Elimination Promotion). It was there I learned that a person can carry Hepatitis C for 20-30 years and not know they have the virus. The only way to find out is to get tested. Some people may think that the only way you get Hepatitis C is through drinking or using needles and you can, but you can also get it through blood transfusions, tooth extractions, or unsterilized instruments in surgery.

The one thing about Hepatitis C is that it is curable. If not treated it affects your liver and you can die from it. I believe all the survivors from residential school should get tested. Through no fault of their own, they may have caught Hep C and it's better to know then not know. Remember that it can be cured and ECHO+ brings liver doctor support to communities to help us get cured.

Beatrice Bullshields

HEALING

Oki, My Name is Charles Bullshields. I'm a member of the Blood Tribe, a member of the Blackfoot Confederacy. I was sent to Residential school when I was 6 years old and spent 8 years there. In 1969 I was sent to Vancouver, BC for a placement program and lived with 'non-natives', but my dad decided not to send me back the following year. I started to drink alcohol and smoke cigarettes at the age of 13 and dropped my first LSD pill at 17. I dropped out of school in the early '70's and moved away from the reserve to Seattle Washington in 1971 to stay with an aunt and uncle for several months while working at odd jobs. One weekend they had a native conference in downtown Seattle, and I decided to go to the pow-wow and meet up with some friends and decided to go to the bar and party. I was so amazed at the night life that I fell in love with it right away. I found myself going downtown more often, until I eventually moved from my relative's safe home and became a street person. I got into drinking, shooting up speed and dropping LSD for the next few years. I left Seattle in the summer and went home to attend our annual Indian Days and moved back to Seattle for the winter. Things got worse for me as time went on. I didn't do drugs to much anymore and just drank alcohol from that time on.

I finally moved home after two men strong-armed me. They had just got out of prison that day. I moved home and never returned to Seattle from that time on. While living in Seattle I had crossed paths with my wife in 1974. She carded me for my I.D. while working as a barmaid in Spokane, Washington. We met again in 1986 in Lethbridge Alberta and have been together since then.

My Mother died in 1992 and I missed her so much that I decided to get away and I went to Vancouver and spent several weeks there. I ran into an old friend and decided to party with him. My friend's girlfriend and several people came in and started shooting up heroin. I was finally talked into shooting up but then I began losing the feeling in my legs to the point of getting rubbery. I couldn't stand up for a period of time until I started to get the feeling back in my legs. I decided not to shoot up heroin ever again.

My wife quit drinking after our daughter's first child in 1999. She decided to quit because she didn't want our grandchild to see her drink, and I quit drinking a year later in 2000. We wanted to change our lives. I sold a drawing to the school near Cranbrook, and they asked me to teach an art class, the first one was hard because I was so shy and not sure how to share my skill, but they liked it and I did this for several years.

In 2013 I was diagnosed with Hepatitis C. My doctor didn't know then how long ago I got the disease, probably the one time in 1994 with that heroin was when I got it. I was told I qualified for a 12 week program and that it was 98% curable. I went through the ECHO+ program and I am now cured from the disease. My wife Beatrice was very fortunate that her immune system was strong and pushed the disease out. My Sister passed from Hepatitis C Liver Cancer years ago and my Cousin currently has stage 4 Cirrhosis and is waiting for a liver transplant. I feel it's very important to get tested for Hepatitis C and get the treatment to be cured. People should be tested because Hepatitis C can be cured.

Creator got me to meet good people throughout my journey even when I was in a bad way. I joined the Horn Society in 2012 and transferred our medicine bundle in 2019. My wife and I went full circle from alcohol and drugs to sobriety and strong spirituality. I lost everything, even my spirituality because of alcohol and drugs, but Creator guided my journey, and was watching me all those years. When there is no one else to talk to, talk to Creator.

We don't want to see you in this situation, or living the life we lived. Hepatitis C is curable and if you get it treated now maybe it will save your life before cirrhosis and liver cancer affect you. It is important to listen to others, and important to get tested and find out about things like Hepatitis C so that people can help you and your body can heal.

Charles Bullshields

A NEW START

I am from a good family, I grew up with both my parents and a good upbringing. In 2013 I was going to college in Lethbridge and I met up with a group of friends who were into drugs and I tried it. That one time was all it took for me to be addicted. At first I thought I will just be high for a week and then quit, but I couldn't quit because then I would feel the pain in my body when I didn't have it and so I felt like I needed it. That one time with carfentanyl was all it took, and I spiraled down from that day.

I dropped out of school, I didn't finish college, I started harder drugs, carfentanyl and crystal meth. My parents kicked me out because I couldn't quit. I was living on the street and I was a continuous user, living a street life every day. I tried to get myself back into school in 2018. I got into Red Crow College, going house to house sleeping where I could, trying to pass classes, trying to get to school every day, still using.

I lost contact with my family, I was someone they just didn't know.

I overdosed on January 21, 2019. I had a choice, I could go with the police or I could go to the detox centre. Of course I went to detox because I realized I needed help. They screened me for Hepatitis C and I found out I had it. I was using intravenous drugs and I don't know when I got the virus.

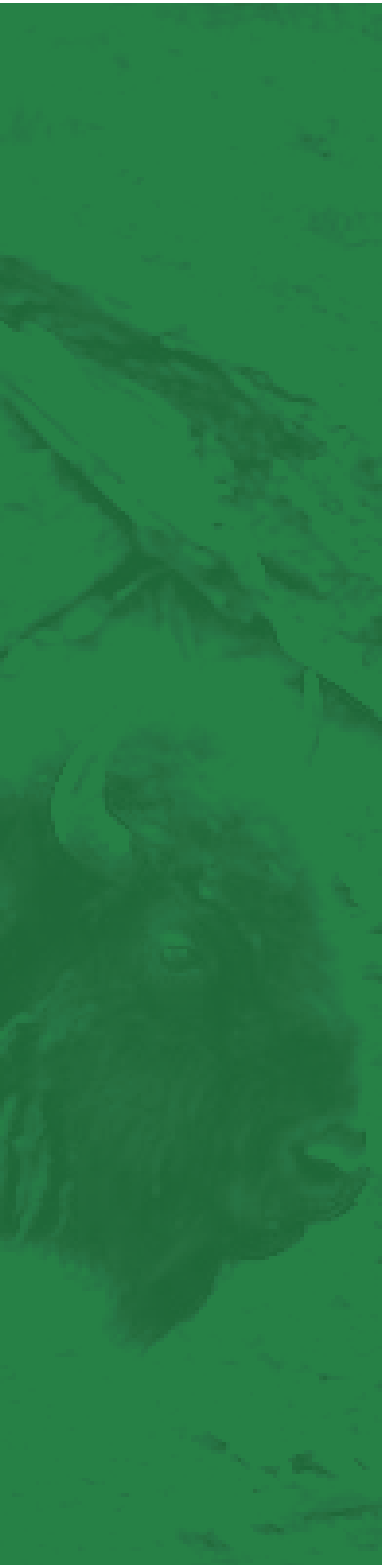
I went on the 12 week treatment through the ECHO program while I was in treatment. I stayed until March 1st. I got accepted at the transition centre at KCC, then I got into the Grouard treatment centre, I was there for 56 days until May. Following that I went back to the transition centre for about 7 months where I got a job as a peer support worker in the detox centre.

I got the lab results that my hepatitis C was cured the day I shared my story at the Liver Health Community Day and that was a big day for me and exciting news. Recently I just got put on full time, and I start on the 29th for 44 weeks back in school to be an addictions and community service worker. The team at the detox centre has encouraged me and supported me and is helping me move forward with my life, and the ECHO+ team has been supportive and they have our best interest at heart.
People don't understand, this infection is curable, I know there is a stigma behind it, some think everyone is going to judge you for having it, or for taking the medication for it.

Don't be scared, it's a good thing and it is going to change your life. Once you get it all done, your next chapter will start, don't be scared.

Mercedes Russell

VISION: PARTNERING THROUGH INNOVATION TO INCREASE ACCESS TO RESOURCES AND TREATMENT FOR HEPATITIS C IN ALBERTA.



SUPPORTING THE STORY

CONTINUED FROM PAGE 11

Continuing to focus on the story of the ECHO+ program included spending time checking in with community healthcare providers and healthcare team members asking how the ECHO+ program can provide better support and linkage to care for hepatitis C in remote and Indigenous communities. A strength of ECHO has been the increased attention on hepatitis C virus (also referred to as Hep C or HCV) while simultaneously providing a solution. ECHO+ provides an opportunity for networking and sharing stories at the annual liver conference. Because ECHO+ provides a supportive non-intimidating space while providing professional support community specific stories evolve and grow as different supports and connections to care are needed. Interviews, circle conversations and surveys provide opportunities to improve the program based on feedback received. Feedback included a request to simplify the case presentation form and make it a 'fillable field pdf', creation of a step by step guide to preparing a case to present, increase communication through a newsletter and create culturally relevant awareness resources. The ECHO+ team facilitated these requests and has shared the resources across the province, including printing and shipping 8,000 copies of the translated booklet on the myths and facts of hepatitis C. The ECHO+ team also advocated with the provincial laboratory leadership to decrease virology reflex cancellations and collaborated to increase access to screening options.

Booklets translated and available in Blackfoot, Cree, Dene, English, Michif, Stoney Nakoda.

Monthly newsletters provide an opportunity share stories, training opportunities, upcoming events and the latest updates around the province. Digital storytelling is another media the ECHO+ team has used to share story and encourage others to share stories of success and healing.

Stories and feedback from community healthcare teams in the spring of 2020 and spring of 2022 report the ECHO+ program provides access to specialist care and treatment for hepatitis C that these patients would not get otherwise.

> ***“Love this specialist model”***
>
> ***“No one would know about hepatitis C here without ECHO, it’s so easy and accessible, no one would get treated otherwise”***
>
> ***“ECHO has opened so many doors for our people to get treatment, made it easier, and awareness too, it wouldn’t have happened if we hadn’t connected with ECHO, it’s really, really great”***
>
> ***“The biweekly session make it easy to connect with the specialist, this format is informative, easy to present, yes this format should be used for other specialist care practice because so supportive.”***
>
> ***“I didn’t know about HCV until I heard about it thru the ECHO sessions.”***
>
> ***“I love the ECHO project, it’s fantastic. It gives nurses autonomy to go out, find and treat.”***
>
> ***“Being able to tell people you can be treated for Hep C, and we can do it onsite. Hep C is curable and easy to cure here. One stop shop!”***
>
> ***“Instead of figuring out what to do if they test positive, we are bringing the care to the people instead of taking to the people to the care.”***
>
> ***“Having a support team availability, it’s been transformative for how we are able to treat patients out here.”***
>
> ***“We have treated all the known cases in our community, they never would have gone for specialist care and never would be cured if not for ECHO.”***

SHARING KNOWLEDGE AND LEARNING TOGETHER

ANNUAL CONFERENCES

The ECHO program has held annual conferences for 5 years featuring professional presentations from internationally recognized specialists on liver health issues. Feedback from attendees led to a shift in focus that includes more community level interests and time for networking and problem solving among attending community healthcare teams in a conversation circle format. These conferences provide excellent presentation with updates from the latest treatment options for various liver health issues and connect attendees to innovations, opportunities, resources and supportive networks as well as providing an educational opportunity.

COMMUNITY GUIDANCE

Indigenous Knowledge Keepers, Elders and community members shared traditional knowledge related to liver health, wellness perspectives, cultural guidance, protocol and resource co-design throughout the ECHO+ program.

VIRTUAL PRESENTATIONS

Pandemic restrictions limited the ability of the ECHO+ team to travel and connect with community healthcare leadership and practitioners, so virtual awareness presentations were developed and shared with many of the Indigenous and remote communities across Alberta. Providing an opportunity to connect with updates to the commonly held myths and misunderstandings that contribute to the continuing stigma surrounding hepatitis C. The presentations included visuals, and explanations of what the liver does, who hepatitis C can be shared between people and what we can do together to prevent and cure hepatitis C. The ECHO+ team adapted the virtual awareness presentations to the audience at each community site, and provided content applicable to the audience.

Awareness and engagement with community health centres where there is a regular doctor or nurse practitioner staffed were included in the awareness conversations. Communities without a regular healthcare provider the presentation was geared toward nurses, peer counselors, or CHRs, this provided an approachable, informative and practical program. Each community was presented with the opportunity to access specialist care through the ECHO+ model and supported if they had questions, concerns or needed assistance to begin screening or acquiring educational resources.

PANDEMIC IMPACTS

The COVID-19 pandemic impacted community healthcare teams ability to screen for anything besides the COVID-19 virus, this also prevented expansion for sexually transmitted and blood borne infections (STBBI) or other health conditions. Our goal to personally connect with every Indigenous community in Alberta with hepatitis C awareness resources and events was not possible during the pandemic and necessitated a shift to virtual engagement. The pandemic also impacted the lab capacity for processing screening tests and ability of people to get to clinics or community centres for screening. This resulted in a drop in cases presented through the ECHO+ Zoom case presentation sessions, and a drop in treated and cured people across the province. To provide relevant support during this shift in priorities an Infectious Disease Specialist from Ontario joined the biweekly Zoom sessions and supported an open question and answer session on COVID-19 related questions.

PROFESSIONAL CONTRIBUTIONS AND SHARING KNOWLEDGE

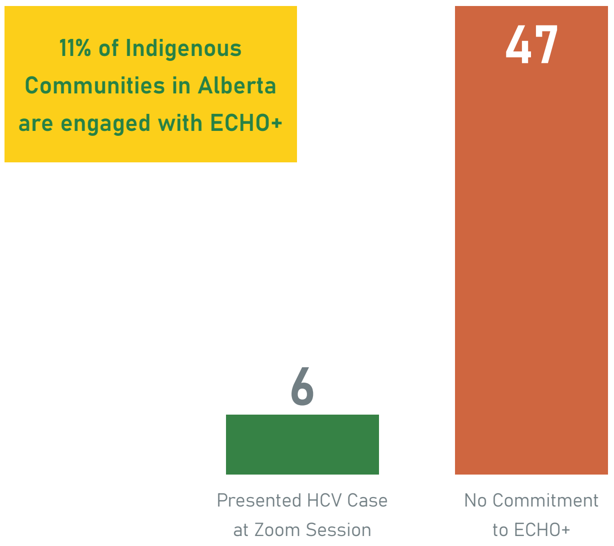
The ECHO+ team worked together to contribute several abstracts and posters for professional conferences around the world, as well as interviews with the Canadian Broadcasting Corporation and the Canadian Liver Foundation. Professional journal articles written by the team were published in the Canadian Liver Journal and the Lancet Gastroenterology & Hepatology Journal.

ECHO+ SUMMARY

Throughout the ECHO+ story the goal has been respectful engagement while supporting a wholistic wellness journey in collaboration with communities across Alberta. Although there is so much more to the story than just numbers, sometimes numbers are also helpful to fill in parts of a story. When the ECHO+ program shifted its focus in early 2020 with the Health Innovation Implementation and Spread (HIIS) funding there was engagement with 11% of Indigenous communities in Alberta. Following the focused communication efforts of the ECHO+ team and the collaboration with community needs and co-creation of relevant and requested resources the engaged communities increased to 92% in the fall of 2021. This illustrates the importance of working together, communication and flexibility to what current needs are.

COMMUNITIES ACCESSING ECHO+

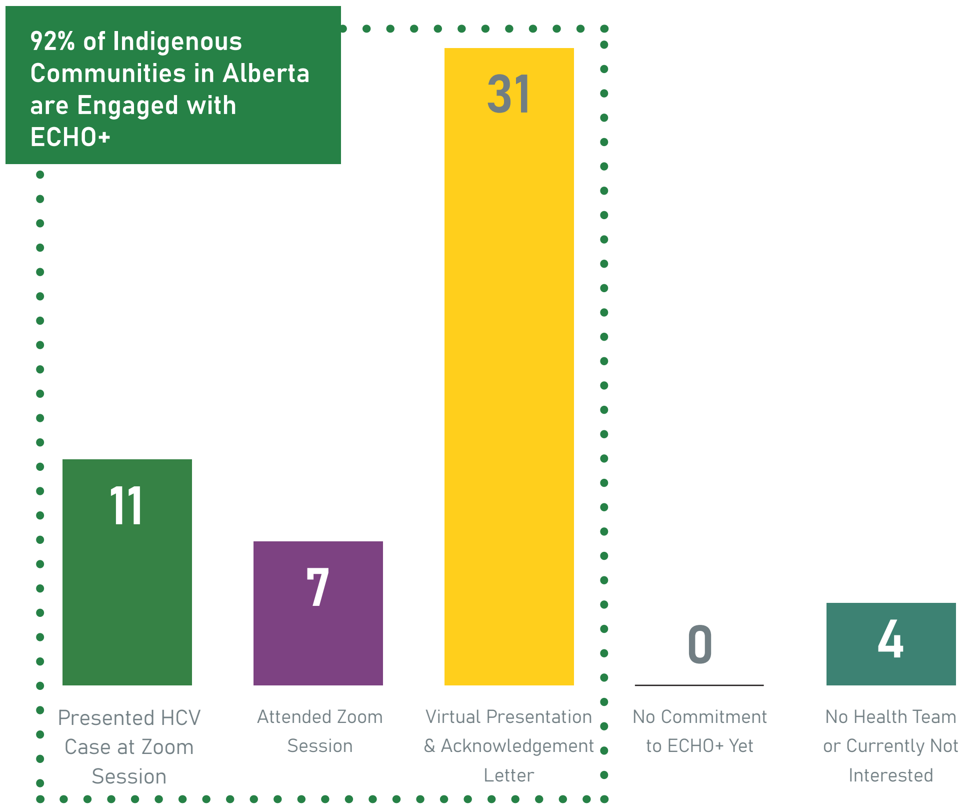
SERVICES WINTER 2020



11% of Indigenous Communities in Alberta are engaged with ECHO+

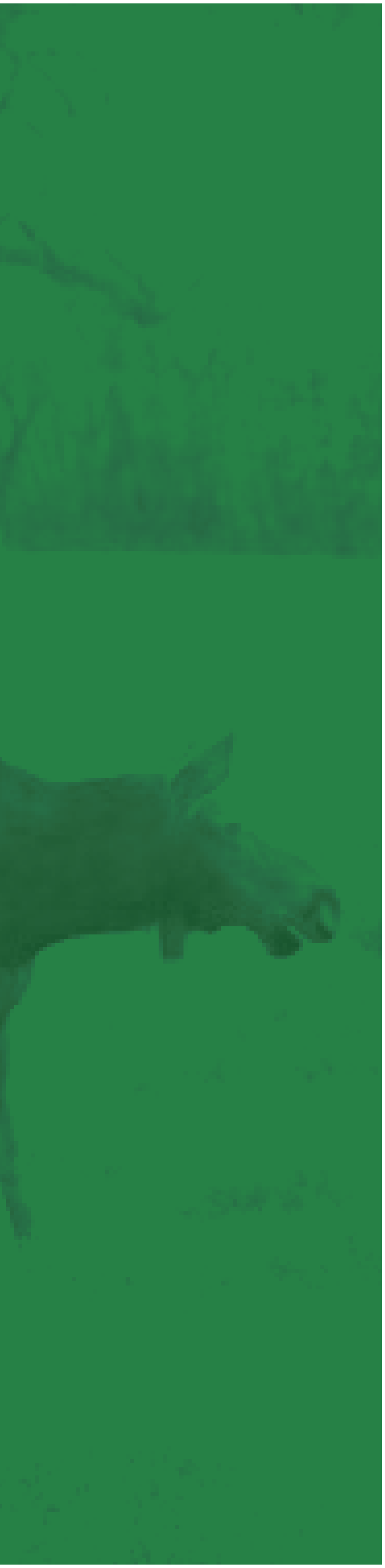
COMMUNITIES ACCESSING ECHO+

SERVICES FALL 2021



92% of Indigenous Communities in Alberta are Engaged with ECHO+

Comparison of engaged communities in Alberta, winter 2020 to fall 2021.



MOVING FORWARD TOGETHER

ECHO is a program with a history, a story, and a vision. As we shift into a new phase of the program we have goals to increase relevant resources for social media sharing, to expand supports and resources, and to collaborate with organizations supporting a smoother and faster path between screening and cure. We plan to facilitate awareness and screening events in collaboration with communities and organizations as we work on micro-elimination projects with interested communities. And everything we do works toward the goal of hepatitis C elimination.

What is your part in this story? We all have a part to play. Maybe it is increasing your own knowledge about hepatitis, or sharing resources with others, or getting yourself screened, or funding a community event, or advocating with your community leadership to support an awareness event, there are many options in working toward elimination of this curable infection in Alberta.

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ECHO+

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