Happy New Year to all Health Care providers that work together to ensure quality care for patients living with life limiting illnesses, and for those close to them. Hoping that you had a wonderful holiday and Christmas season filled with what matters most to you.

The Provincial PEOLC team would like to begin 2020 by celebrating our progress with you. In 2014 the PEOLC Alberta Provincial Framework (https://www.albertahealthservices.ca/assets/info/seniors/if-sen-provincial-palliative-end-of-life-care-framework.pdf) was published to help fill gaps in PEOLC programs and services and to improve the quality of existing PEOLC program and services. Over the past five years since the development of the Framework, the PPAL/EOL ISC has implemented approximately 20 of the 36 recommended initiatives and Alberta is recognized nationally for our innovative and integrated PEOLC programs and services.

To optimize engagement and make the best use of everyone’s time, in the new year, PPAL/EOL ISC will now be meeting bimonthly, beginning on February 20, 2020.

In the year ahead, this newsletter will start to highlight a frontline PEOLC clinician in each issue – see page 4 to learn more about Leah Johnson-Coyle, a Palliative Nurse Practitioner in the Edmonton Zone.

There continues to be progress on the identified gaps and outstanding initiatives as the 2019/20 year wraps up. The Provincial PEOLC team will also be completing some initial planning and proposing priorities for the 2020/21 fiscal year to PPAL/EOL ISC in the Spring.
Advance Care Planning / Goals of Care Designation (ACP/GCD)

Any questions please contact conversationsmatter@ahs.ca

Please check out the additional Frequently Asked Questions (FAQs) that address clinical issues (including choking, cardioversion, and more), which are now posted online https://www.albertahealthservices.ca/info/Page15938.aspx. Thank you to those of you that contributed and reviewed these FAQs.

The updated Conversations Matter Guidebook has now been translated into 7 key languages – Arabic, Simplified Chinese, Traditional Chinese French, Punjabi, Spanish and Vietnamese. The Conversations Matter Guidebooks (English and 7 translations) can be viewed online at https://myhealth.alberta.ca/Alberta/Pages/advance-care-planning-resources.aspx. To order print copies of these resources, please visit www.conversationsmatter.ca, click on health professionals, and then click on the supplies tab for ordering instructions.

ACP and GCD are included in Connect Care, Alberta’s upcoming provincial unified electronic health record. Wave 1 launched on November 3, 2019, and included hundreds of outpatients clinics, services and specific sites within the Edmonton Zone. Patients or healthcare providers are able to upload and view the Personal Directive, GCD order or ACP/GCD Tracking Record. If patients submit documents, they are validated by Health Information Management and then also reviewed by a healthcare provider before being uploaded to the patient’s health record.

The Provincial ACP/GCD Community of Practice continues to meet bi-monthly to support each other by sharing information on the topics of ACP/GCD integration, education and evaluation. Recent discussions have included clinical issues, tips for physician engagement, research, and national projects and resources.

AHS is also meeting quarterly with ACP Alberta, Alberta Health and the Office of the Public Guardian and Trustee, to share updates and discuss future plans and connections regarding ACP/GCD in Alberta.

Palliative and End of Life Care Website
https://myhealth.alberta.ca/palliative-care

All PEOLC pages on the MyHealth Alberta PEOLC website for the public (https://myhealth.alberta.ca/palliative-care) have been reviewed and updated by the Provincial PEOLC Website Working Group.

The provincial PEOLC healthcare provider landing page has also been redesigned and posted https://www.albertahealthservices.ca/info/Page14559.aspx.

The palliative.org website has been decommissioned, and nearly all of the content has transitioned to the provincial PEOLC website for the public and for healthcare providers.

A helpful resource on the public provincial PEOLC website is information about Final Days at end-of-life - https://myhealth.alberta.ca/palliative-care/resources/final-days.

This includes the following sections:

- Overview
- Trying to understand
- When death gets closer
- Ways you can help
- What to expect
- When death happens
- Resources
Advance Care Planning (ACP) Collaborative Research & Innovation Opportunities (CRIO) Program

It’s hard to believe that the Alberta Innovates-funded Advance Care Planning Collaborative Research and Innovation Opportunities program (ACP CRIO) has come to its close!

With enormous gratitude to many, many advance care planning champions and supporters, ACP CRIO achieved nearly everything it set out to study and more, from our start in 2013. With over 6000 participants across 19 studies, 120+ network members, 16 trainees supported, and 100+ conference presentations, this reach is evidence of our efforts to increase research capacity, advance knowledge, and inform decision-making around advance care planning in Alberta, to ultimately help improve the quality of person-centred care.

What did ACP CRIO find? Check out the “Research Impact Report: 2013 -2019” at www.acpcrio.org for a summary of our findings. We’d love your feedback on the report, and this new website! The ACP CRIO website will remain active as a resource and repository of the programs work.

What’s next for advance care planning in Alberta? Optimally implementing ACP and GCD’s across a complex health care system takes many partners both within and external to the health system, including legal, public and government partners. ACP CRIO, Alberta Health, and the Office of the Public Guardian and Trustee have been collaborating on a proposal for “ACP Alberta” that will build on what has been learned from ACP CRIO, using a government and non-government collaborative to strive towards a public action plan for advance care planning. Stay tuned for further details!

Connect Care—Palliative and End-of-Life Care

November 3, 2019 marked the launch of Wave 1 of Connect Care, the first stage of the province wide electronic clinical information system for AHS.

Over the last year, PEOLC experts from across the province have been participating on the Connect Care PEOLC Specialty Design Working Group to provide input and make decisions on various components relating to PEOLC for Connect Care. Under the direction of the Continuing Care Connect Care Area Council, the PEOLC Specialty Design Working Group met bi-weekly to work through 47 decisions to prepare for implementation.

Recently a walkthrough of the commonly used screens and assessment tools were provided to the PEOLC Specialty Design Working Group. The biggest challenge that was mentioned is the time it took for clinicians to learn the system and where to find the information they needed. The next step is to work through the challenges and fix issues that have been identified by users prior to the next wave.

There are nine implementation waves in total occurring between late 2019 and late 2022. Click on the following link for the latest information about Connect Care and timelines - https://www.albertahealthservices.ca/info/cis.aspx
My name is Leah Johnson-Coyle and I am a Nurse Practitioner (NP) in Palliative Home Care (PHC) for Urban Edmonton. This role of the NP in PHC is a very diverse one. With the growing population of palliative patients in the community who want to be at home at end-of-life, combined with a changing health care system, and an ongoing effort to transition patients back into the community setting, the role is ever changing. There also seems to be less General Practitioners in the community whom are willing to do home visits, and even less with Palliative care experience.

Our population is largely Oncology, however there is also a growing population of patients with chronic diseases who are being palliated in the home setting; including Heart Failure, Chronic Obstructive Pulmonary Disease (COPD) and Interstitial lung disease (ILD), as well as neuromuscular illnesses.

As the NP role within PHC, I am the primary care provider for these patients, managing symptoms at end-of-life, prescribing medications for their ever changing conditions, as well as ordering and facilitating diagnostics and procedures in the community. We work closely with the Edmonton Zone Palliative Community Consult Team to facilitate complex symptom management and transfer to hospices in the area and/or the Tertiary Palliative Care Unit at the Grey Nuns when appropriate.

As both an RN and an NP I worked in various Critical Care Units for 14 years, specifically in Cardiovascular Intensive Care Unit (CVICU) at the Mazankowski Alberta Heart Institute for nearly 10 years as an NP. I have always really been drawn to Palliative care and the complex situations faced at end-of-life, when this job became available I knew I had to know more. I have been in this position for 14 months and love how the role has transpired and continues to evolve. I truly love the relationships I am privileged to create with the families I work with so intimately, and the staff I rely on and whom rely on me.

Outside this life, I am also a mother to twins who are 7, Molly and Finley, and wife to a fabulous husband, Tom. This role has really allowed me a balance in life of being a full time working mom when life is full! I am so grateful to have been given this chance to build such a diverse and ever changing role within a community I am so incredibly passionate about.

The provincial Rural Palliative Care In-Home Funding Program will enhance care in the community and give the required end-of-life care supports in rural and remote areas so clients will be able to stay in their own home instead of being admitted to acute care.

Two patient and family leaflets have been developed to provide an introduction to the program and additional information on the services available. For AHS staff, these leaflets are available on InSite under Palliative and End-of-Life Care on the Seniors Health page.

The provincial team have been meeting individually with zones to support the implementation of the program. South, Central and North Zones will be implementing the program by March 31, 2020. Seniors Health is also looking at ways to collect and collate data on the program from the zones.

The next working group meeting this month will look at learnings and challenges.

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AHPCA hosted its Imagine 2019 conference in Red Deer this fall, bringing together over 20 hospice palliative care groups from across Alberta. The annual event strengthens connections between groups with the intention of creating a robust, well-informed palliative care community in Alberta.

Attendees were welcomed by AHPCA’s new board chair, Elaine Klym, who was elected just the night before at AHPCA’s Annual General Meeting. Jason Stephan, MLA for Red Deer-South brought greetings from the Alberta Government and an invitation for attendees to further his learning by contacting him with any palliative care roadblocks they may encounter. Be sure to take Jason up on his offer by contacting his office at RedDeer.South@assembly.ab.ca.

Michelle Peterson Fraser, AHS Director, Palliative and End-of-Life Care, Community, Seniors, Addiction & Mental Health, updated attendees on AHS’s Rural Palliative In-Home Funding Program.

In her keynote address, Sarah Walker, Health Consultant and former Hospice Calgary Executive Director, spoke about providing end-of-life care at home and supporting the home in that endeavour. What do people want to experience at end-of-life? How can communities support patient and family needs? One way is building organizations and programs. While the goal may be common, each community is unique and each program will reflect its community. Before lunch, AHPCA was proud to present its Dr. Donna Wilson Caregiver Award to 2019 recipient Joyce Skopik.

In the afternoon, Imagine 2019 heard local stories from six community groups, all of whom have developed unique ways to support families and patients who prefer to die at home. Attendees heard stories of innovative programs and partnerships from Wheatland & Area Hospice Society (Strathmore), Compassionate Care Hospice Society (Rocky Mountain House), Olds and District Hospice Society, St. Albert Sturgeon Hospice Association (SASHA), Cochrane Hospice Society and the Red Deer Hospice Society.

It was a meaningful day spent learning, sharing new ideas, forging new and strengthening old connections.

Palliative Care, Early and Systematic (PaCES) Update

The new clinical practice guideline “Integrating an Early Palliative Approach into Advanced Colorectal Cancer Care” is one year into implementation in Calgary!! Are you curious about the impact so far?

PaCES set out to improve care coordination and timely access to palliative care for people living with advanced colorectal cancer, and the first year of data show it’s achieving that and more! Oncology clinicians in the gastrointestinal cancer clinics in Calgary have adopted the use of “shared care letters” to connect family doctors, patients and the oncology team. Data from April to September 2019 show ~30% of all advanced colorectal cancer patients coming to the cancer centres now have a shared care letter ordered. Of these, >50% of family doctors have faxed back their response to the shared care letter, confirming their role as the patient’s “medical home” and initiating a closer relationship with the patient’s oncologist. Additionally, over 50 patients have been referred to the PaCES early palliative care consultant providing care consultations in patients’ homes, and about one-quarter of all advanced colorectal cancer patients have now received a referral for home care.

We will continue to evaluate the impact of this innovative program on patient, caregiver and health system outcomes until 2021. Results of the PaCES project will inform the spread of an early palliative approach to care to other cancers, so that more patients can receive coordinated, personalized, supportive care to support their well-being, despite advancing illness.

Visit www.ahs.ca/guru to view the pathway and accompanying resources. For more info on PaCES see www.pacesproject.ca.
Canadian Hospice Palliative Care Association (CHPCA) Update

CHPCA and CSPCP - Joint Call to Action

Due to ongoing confusion amongst the general public regarding Hospice Palliative Care (HPC) and Medical Assistance in Dying (MAiD), the Canadian Hospice Palliative Care Association (CHPCA) and the Canadian Society of Palliative Care Physicians (CSPCP) released a joint statement, on November 27, 2019, to clarify the relationship of HPC and MAiD.

Read full statement here: https://www.chpca.net/news-and-events/chpcacspcp.aspx?

2019 Canadian Hospice Palliative Care Conference

The 2019 Canadian Hospice Palliative Care (CHPC) Conference took place once again in Canada’s beautiful capital - Ottawa, Ontario from September 19th to 21st, 2019. The CHPC Conference hosted over 400 health professionals, comprised of physicians, nurses, administrators, social workers, therapists, pastoral care providers, academics, volunteers and students. Presentations highlighted the conference’s seven streams: Clinical Practice, Advance Care Planning, Integration: A Palliative Approach to Care, Public Health & Compassionate Communities, Research & Knowledge Translation, Policy & Advocacy, and Indigenous Community.

The conference featured eight challenging issues panel sessions – highlighting the most cutting edge topics in palliative care, three plenaries, over 60 scheduled workshops and oral presentations, more than 80 poster presentations, and much more.

This successful conference also highlighted a number of networking opportunities including a wine and cheese reception, networking lunches, and an evening of entertainment featuring comedians followed by dancing!

The CHPCA is currently underway with planning for the 2020 Learning Institute. The 5th event of its kind is to be held in Ottawa, ON, from June 4th – 6th, 2020 at the Ottawa Marriott Hotel. The Learning Institute is an intimate gathering of hospice palliative care practitioners with a focus on intense learning.

The next Canadian Hospice Palliative Care Conference will be occurring in the fall of 2021.
November 19, 2019, was the annual National Bereavement Day in Canada. This year’s theme was “coping with grief, together through living and grieving.” The 2019 digital campaign aimed to encourage individuals and groups to learn about grief and bereavement.

Throughout the month of November, CHPCA promoted several resources and tools to help Canadians throughout their grief journeys – for those dealing with grief, bereavement, anticipatory grief, ambiguous grief, and chronic sorrow.


The new framework is restructured to focus more on broadening partnerships, and promoting further collaboration among different jurisdictions (local, provincial/territorial, national) and systems (health, law, social services, life planning). Its development was funded by Health Canada as part of a $1.9 million project over three years to help people living in Canada prepare for their future health care needs.

https://www.advancecareplanning.ca/acp-framework/
Living Well, Planning Well

The ‘Speak Up’ Advance Care Planning in Canada initiative released two complementary resources to support public navigation of the legal requirements and facilitate lawyers’ involvement in their clients’ ACP. With these two resources, you have a better access to plain language explanations of your rights and requirements in ACP, and lawyers have an aid for initiating ACP conversations with their clients, should they wish. Together, these resources enable more opportunities for people in Canada to exercise their rights to plan their future care.

Public Toolkit

Speak Up and the BC Centre for Palliative Care developed a complementary “Living Well, Planning Well” resource for the public. A national Advisory Committee of legal professionals, health care providers, and patient and caregiver representatives supported its development. Funding for this resource was provided by the Canadian Bar Association’s Law for the Future Fund grant program.

Learn more

Lawyer’s Toolkit

The legal toolkit is designed to help lawyers and their clients go through the process of ACP. The toolkit provides information about the importance of ACP and its role within future life planning in general (e.g., estates and wills, life insurance, investment planning). It also covers different scenarios, prompts, and precedent clauses that lawyers can use to start ACP conversations with their clients.

Learn more

Zone PEOLC Operational Dyad Meetings

Over the last year a number of Zone PEOLC operational leaders have mentioned that it would be useful to have a venue where all the PEOLC Dyad partners from each zone could meet to discuss learnings and challenges and also to share ideas and resources. In response, the provincial PEOLC team is facilitating bi-monthly Zone PEOLC Operational Dyad meetings, bringing together zone adult and pediatric PEOLC Operational Leadership Dyad partners and the Palliative Institute.

This group will work together with the provincial PEOLC team and PPAL/EOL ISC to improve the quality and access of PEOLC for all Albertans. The Zone PEOLC Operational Dyad meetings are an opportunity to enhance collaboration with Zone PEOLC Operational Leaders across the province.
**Palliative Care Competencies**

THANK YOU! to the many individuals that have come together to create Alberta Palliative Care Competencies for their disciplines.

Competencies have been completed for Occupational Therapists, Physiotherapists, Paramedics, Nursing (RN, LPN, RPN), Health Care Aides, and Respiratory. Seven more disciplines: Advance Practice Nurses (CNS & NP), Speech Language Pathologists and Audiologists, Dietitians, Psychologists, Medical Radiation and Imaging Technologists, and Pharmacists, are in the process of completing their work. We are now starting to recruit for Spiritual Care, Social Work and Volunteers to begin work in late January.

Pan-Canadian Inter-Professional Palliative Care Competencies are being created by the Canadian Partnership Against Cancer (C-PAC) for generalists (caring for palliative care patients and their families in all care settings) and for specialists (health care providers whose practice is focused on palliative care and consultation) for Volunteers working in Palliative Care, Social Workers & Counsellors, Nurses (RN, RPN, LPN, CNS & NP), Personal Support Workers (HCAs), and Physicians.

**ACP/GCD with Surgery Patients**
The Misericordia Community Hospital (MCH) in Edmonton has embedded ACP/GCD into caring for patients with fractured hips requiring surgery. In the new year, the MCH will be implementing ACP/GCD into caring for all surgery patients.

**Palliative Care Glossary for the Health Standards Organization (HSO) Palliative Care Services Standard**
The Health Standards organization are just completing the final report which will include consensus based definitions for palliative care, palliative approach to care, quality of life, pain and symptom management, caregivers, life limiting illness, and serious illness. Stay tuned for the definitions for these terms we so commonly use.

At the February Provincial Palliative and End-of-Life Innovations Steering Committee meeting there will be discussion about definitions and if the PEOLC Alberta Provincial Framework definitions should be edited or not.

**Edmonton Classification System for Cancer Pain (ECS-CP) National Study**
Assessing the generalizability of the ECS-CP in various settings (inpatient tertiary palliative care unit, outpatient palliative care clinic, acute care and community) this study is well underway with Whitehorse, Vancouver, Edmonton, Calgary, Montreal, Ottawa, Kingston and Toronto participating.

For PEOLC education opportunities, review the Provincial PEOLC Education Bulletin link. www.albertahealthservices.ca/info/page14438.aspx

- AHPCA Road Show—Scared to Death of Death
- Hospice Calgary—Dying to Know 2020 sessions
- World Café Research Study Invitation
- North Zone Education Sessions
- 30th Annual Palliative Education & Research Days
- Upcoming Professional Development opportunity sponsored by the U of C, Faculty of Social Work and AHS
Happy New Year from the Central Zone Palliative Care Team.

The Central Zone’s palliative/hospice societies are significantly important in providing care and education to the communities. The Palliative Care team continues to support and collaborate with them. Olds and Wetaskiwin have recently trained more volunteers in PEOLC and Grief/Bereavement and we look forward to working with more communities in the spring of 2020. On June 2, 2020 there will also be training for Nobody Dies Alone (NODA) available via teleconference. The Red Deer Primary Care Network has invited us to facilitate Serious Illness Conversation Guide (SICG) to their physicians and staff; there will be several other SICG classes throughout the spring; dates TBA.

Camrose Hospice Society is offering a two day course on child grief support training. This course will be held on January 23-24, 2020. Please visit www.camrosehospice.org for additional information. The society has also trained more volunteers and expanded their reach into rural Central Alberta with NavCARE and offering grief support. Camrose Primary Care Network Palliative and End of Life Care – Community of Practice group is meeting to share knowledge, identify gaps in service, prioritize needs and develop, implement and evaluate solutions unique to palliative clients and their families in the community of Camrose and area.

Rocky Mountain House has opened their first hospice suite at Good Samaritan Clearwater Centre. They have worked hard over the last few years in order to make this dream a reality. The space is a comfortable two-bedroom suite for the patient and up to three family members. With a bathroom, living room, pull-out bed, stove and fridge, the suite enables families to spend private, quality time with their loved ones. This new hospice space offers families the option of a private, home-like setting and allows family members to spend as much time as they like with their loved one to offer comfort and care.

Hello and Goodbye

The North Zone Palliative Care team would like to welcome Michelle Bespalko to the Palliative Care Resource Nurse position in Area 8 (St. Paul/Cold Lake/Elk Point/Bonnyville). Michelle joins the team from a long tenure with St. Paul Home Care, where she has been Team Lead for the last several years. Previously, Michelle worked in both long term and acute care in communities around St. Paul. She has a passion for palliative care, and has supported many palliative patients during her time in home care. Michelle is excited to join the team, and we are looking forward to adding her skills and experience to our team.

A welcome also means a goodbye, and we sincerely wish Loretta Manning, Palliative Care Resource Nurse in Area 8, a happy and healthy retirement! Prompted by a fortunate comment from a public health nurse as a teen to consider nursing, Loretta completed her nursing diploma at the Royal Alexandra Hospital in Edmonton, and later her BScN at the University of Alberta Hospital. Loretta’s career includes community nursing in northern BC, Home Care, Public Health and rural acute and emergency nursing. Formerly with the Lakeland Region Palliative Care program, Loretta returned to palliative care in 2014, becoming an important voice in shaping the North Zone program as it has grown. Her compassion for the patients and families always stands out, and her practical approach helped to keep a direct care voice in process development. A LEAP Facilitator and a skilled teacher, Loretta has a keen eye for young talent, and has mentored and supported many new nurses as they gain experience. We wish Loretta all the best for her retirement, expected to include some travel, time with family, and lots of fishing and gardening.

Rocky Mountain House’s Palliative Suite November 2019
EMS PEOLC ATR Community of Practice

On April 1, 2019, the third and final phase of the Emergency Medical Services Palliative and End-of-Life Care Assess, Treat and Refer (EMS PEOLC ATR) program was implemented across Alberta. We thank everyone who contributed to the EMS PEOLC ATR program in various ways, including participation on the Oversight Committee or Working Groups, the work done by Heath Systems Evaluation and Evidence, sharing program experience stories and providing input on protocols and resources. Your contributions have made the EMS PEOLC ATR program a huge success recognized both within Alberta and across Canada.

With the project closing, what we will be focusing on will be ensuring the EMS PEOLC ATR program continues to be sustainable and operational. In order to achieve this, an EMS PEOLC ATR Community of Practice has been established to support front line paramedics, community clinicians and physicians. Membership on the Community of Practice is inclusive of, but not limited to, front line paramedics, community clinicians, AHS EMS & Continuing Care zone leadership, and EMS & palliative physicians. If you would like to participate on the Community of Practice, please speak with your supervisor and have them send an e-mail to ems.palliative@ahs.ca.

EMS PEOLC ATR Evaluation

The EMS PEOLC ATR Phase II Year 2 evaluation report has been completed by Heath Systems Evaluation and Evidence. The report provides a summary of data on the EMS PEOLC ATR program for the period from October 1, 2016 to March 31, 2019.

The following points show event outcomes for the period from October 1, 2016 – March 31, 2019

![Evaluation of the program will continue to March 31, 2021 and include Phase III data.](image)

Zone ATR Reps

North: terri.woytkiw@ahs.ca
Edmonton julia.arsenault@ahs.ca
Central: pansy.angevine@ahs.ca
Calgary: TBD (in the meantime contact ems.palliative@ahs.ca)
South: carolyn.gouw@ahs.ca

Inquiries from EMS related to the Assess, Treat and Refer program may be directed to: ems.palliative@ahs.ca.
On June 20th, 2016, parents Lesley and Patrick Roelofsen were shocked to discover that what they thought were growing pains in their seven-year-old daughter, Thea’s, right leg, were actually aches from a rare form of bone cancer.

After months of intense chemotherapy and radiation treatments, it became apparent that Thea’s cancer was relentless. To support the family through this difficult journey, the Roelofsen’s were introduced to the team at the Rotary Flames House (RFH). For over 80 families like the Roelofson’s, Rotary Flames House has become a warm, welcoming place where respite and end-of-life care has been provided to pediatric patients, and has helped these families get through some of their darkest days.

“I would quickly learn that the team at the House are not about supporting a child to die,” says Roelofson, “but helping a terminally ill child live richly, fully and beautifully until their last breath.”

In October, Rotary Flames House, along with their dedicated, team of multi-disciplinary professionals, celebrated a 10-year milestone. These dedicated staff include physicians, clinical nurse specialists, registered nurses, health care aides, porters, pharmacists, respiratory therapists, lab technicians, social workers, spiritual care practitioners, child life specialists and administrative support as well as various other support and contracted staff.

Over the last decade, this team, along with partners including the Alberta Children’s Hospital Foundation and the Calgary Flames Foundation, has helped make Rotary Flames House a leader in family centred care and one of the most comprehensive pediatric hospices in the country.

“We believe that Rotary Flames House provides light for families in their darkest of days,” says Roelofson. “During heartbreaking struggles and unimaginable grief, there is a place where comfort and peace can be found. RFH gave us time, it gave us quality, it gave us life and it means everything to us.”