



he International Myeloma Foundation (IMF) is one such organization in which rich, reliable, easily accessible and securely-attained patient data is fundamental to reaching its mission. Founded in 1990 and serving 525,000 patients in 140 countries, it strives to help myeloma patients live well with the disease, while working towards better and faster treatments and a cure. Cloud technology is helping IMF do that by educating patients, advancing medical and scientific innovation, unlocking donor insights, increasing fundraising, and more.

Unobstructed access to and meaningful analysis of unsiloed data can enhance the quality of a life or literally save it.

Myeloma, also known as multiple myeloma, is a blood cancer of the bone marrow plasma cells, and the second most common blood cancer diagnosed in the United States. It is a very complicated disease that must be approached from multiple directions. Approximately 35,000 patients are diagnosed with myeloma in the U.S. each year, and worldwide estimates are over 175,000 annually. The disease results in high levels of malignant plasma cells and reduced levels of normal antibodies leading to a compromised immune system. About 160,000 new cases are diagnosed annually. Today Myeloma remains incurable, with patients either managing it throughout their life or ultimately succumbing to it. The IMF is dedicated to improving outcomes for those diagnosed with the disease and continuing to search for a cure.

"Today, health data infrastructure and interoperability continue to provide opportunities for patients to access information faster to help educate and inform on decision-making — all with the potential for an easier user experience," said Yelak Biru, president and chief executive officer (CEO) at IMF, who also lives with myeloma himself. However, disparities in access to health information, services, and technology can result in less knowledge and lower usage rates of preventive services

leaving patients inadequately informed and underrepresented. Additionally, the COVID-19 pandemic exacerbated the access and delivery of healthcare and meeting the needs of diverse populations, which further highlighted the significant importance to measure improvement and outcomes of value-based care.

"The pandemic tested resiliency for both patients and healthcare professionals.

For patients with an immune-compromised cancer like myeloma, telehealth became more and more important, but in many cases was insufficient and left patients struggling to understand information about their disease and how to make the best decisions possible for treatment," Biru said.

Because of the gaps in complexities of care decisions, the IMF is committed to creating a more patient-focused digital ecosystem and advancing its data strategy. That's why it deployed *Data Lake for Nonprofits* — powered by AWS — an offering from Amazon Web Services (AWS) and Salesforce. It helps organizations unify data and glean more insight that lead to informed decisions and the ability to better serve beneficiaries, communities, and stakeholders.

## DATA BECOMES MORE ACTIONABLE, VALUABLE, AND POWERFUL.

Data lakes can store relational data such as structured data from line of business applications like customer relationship management (CRM) systems and enterprise resource planning (ERP) software. They can also store nonrelational, unstructured data from mobile apps, internet of things devices (IoT), and social media. Unlike a data warehouse, which requires time and careful organization, a data lake lets you store data in its native format and explore queries and relationships as needed.



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The IMF uses their data lake on AWS to synchronize Salesforce CRM data and combine it with other patient and donor data to gain insights and improve decision-making. The IMF can visualize the data in its lake with dashboards, use big-data processing and real time analytics for reporting, and build machine learning models to make predictions. Previously, this type of analysis was tedious, manual, time-consuming and drawn from siloed and fragmented information sources.

"The reason we chose to collaborate with AWS and Salesforce is to fuel our digital strategy of providing just-in-time support and education wherever myeloma patients are in their journey," Biru said.

The decision to move away from an on-premises legacy solution is IMF's first foray to the cloud and has given the organization the confidence to accelerate and create enhanced support for all stakeholders.

## **ENABLING BETTER** DATA MANAGEMENT

In the recent Salesforce Nonprofits Trends Report, 76% of nonprofits reported that they are still developing a data strategy. Less than one-third said it was easy to find and share data when there is a problem involving different departments, with 69% saying that sharing data across departments is difficult.



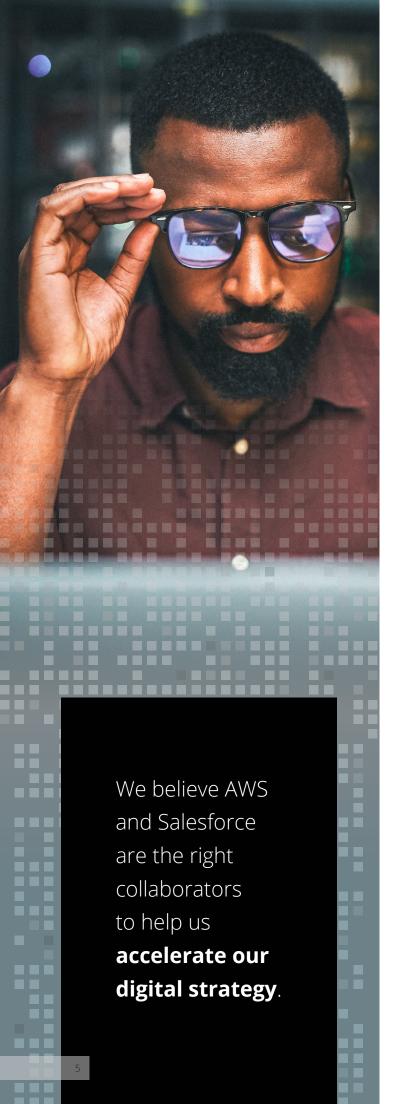
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"What most organizations need is to be able to have a complete view of all of their interactions with their constituents and all their interactions across their programs," said Lori Freeman, vice president of nonprofit industry solutions and strategy at Salesforce. "So, helping organizations develop a data strategy so they don't miss an opportunity to maximize on their fundraising efforts in their program delivery and having the right tools to make sense of the data is really the core of what Data Lake for Nonprofits — powered by AWS solves for."

"We have started collaborating with AWS more deeply over the last couple of years and had a shared set of hopes and accomplishments around how to serve the nonprofit sector,"

Freeman said. "From there, we really were able to focus on what we both share as a belief around a common problem of data strategy. And, helping organizations make their technology choices to have interoperability and flexibility."

The common steps to create a secure exchange of information via the Salesforce Nonprofit Success Pack (NPSP) to a data lake from AWS have been simplified. Data Lake for Nonprofits — powered by AWS has reduced the process of connecting data to the lake from 30 setup steps to six steps — instead of taking weeks, it can be done in hours. Now, nonprofits can spend their time and resources on things that are unique to their organization's needs.



"We are excited to collaborate with Salesforce to meet our customers' needs together," said Allyson Fryhoff, managing director of nonprofit and nonprofit healthcare business at AWS. "By starting with the customer and working backward, we're able to deeply understand their needs and guide them on how to better unify and visualize their data, which allows them to gain powerful insights they can use to make more informed decisions to positively impact their mission outcomes."

"We believe AWS and Salesforce are the right collaborators to help us accelerate our digital strategy," Biru said. "Their solutions and new offerings really know how to support funders, to support grant-makers, and to support the nonprofit sector."

## MOVING FORWARD

Gathering data on patients, donors, and other stakeholders is only a small piece of the puzzle though. Unlocking the value of that data for the betterment and advancement of care and quality of life for people with myeloma is a bigger, more vital goal. The IMF remains committed to being the primary source for patients with myeloma in the areas of research, support, education and advocacy, and ensuring patients find the information they need when they need it by performing machine learning based trend analysis, cohort-based segmentation and recommendation.

Biru and his IT staff look forward to the many ways they'll continue to use *Data Lake* for Nonprofits — powered by AWS. It is just a part of the organization's larger digital strategy, which includes creating the Myeloma Knowledge Platform, which will enable a holistic view of the patient profile, content and resources, along with an artificial intelligence and machine learning analytics engine to recommend relevant information and guidance.

By understanding patient profiles, IMF can then provide a more individualized and meaningful recommendation regarding actions patients can take, clinical trials they qualify for, and which myeloma experts can best assist them in their care journey. And, because patient information contains sensitive data, the project will also be using AWS Key Management Service and other AWS services to protect against security threats and maintain data privacy and compliance.

Download the "Building a Data Management Strategy for Your Nonprofit" whitepaper to learn how to get started with Data Lake for Nonprofits — powered by AWS.

Salesforce and AWS designed this offering to be a user-friendly, guided experience.

A network of qualified AWS Partners is also ready to help you set up your data lake. If you are interested in working with one of these partners, contact one of our AWS account representatives.





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